Family assisted passive exercising of unconscious patients in the intensive care unit: does it make a difference?

By

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Statement regarding published work contained in thesis

At the time of submission, no part of this thesis has been published in any form.

_____ 29th January 2020

Judith Dixon Date

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Table of contents

Declaration of Originality ii
Authority of Access ii
Statement of Ethical Conduct ii
Statement regarding published work contained in thesis ii
Acknowledgements iii
Table of contents iv
List of tables x
List of figures xii
Presentations arising from this research xiv
Glossary of terms xv
Abstract xvii
Chapter 1 Introduction 1
1.1 Introduction 1
1.2 Background 2
1.2.1 ICU admissions and survival implications 2
1.2.2 Treatments for ICUAW 3
1.2.2.1 Passive exercises 3
1.2.3 Needs of ICU families 3
1.2.4 Workplace stressors for ICU nurses 4
1.2.5 Healthcare system 5
1.3 Statement of the problem 6
1.3.1 Patient vignettes 7
1.4 Research questions 8
1.5 Theoretical framework 9
1.6 Research method 10
1.7 Setting and participants 10
1.8 Outline of the thesis 11
1.9 Conclusion 13
Chapter 2 Literature review 14
2.1 Introduction 14
2.2 Search Strategy 15

2.2.1 Scoping review 16
2.2.2 Iterative process 18
2.3 Defining patient and family centred care 27
2.4 Implications of PFCC for the family of patients in ICU 31
2.4.1 Family needs in ICU 32
2.4.2 Families assisting with care in ICU 34
2.5 Implications of PFCC for patients in ICU 35
2.6 Implications of PFCC for ICU nurses 37
2.6.1 Workplace stressors for ICU nurses 37
2.7 Implications of PFCC for the healthcare system 40
2.8 Strengths and limitations of the literature search and review 42
2.9 Research question and significance of the study 42
2.10 Theoretical framework 43
2.10.1 Structure, process and outcome model 44
2.10.2 Picker Institute's eight principles of patient-centred care 45
2.10.3 McCormack and McCance's person-centred nursing framework 47
2.10.4 The study's theoretical framework 48
2.11 Conclusion 50
Chapter 3 Research design and study instruments 52
3.1 Introduction 52
3.2 Research design 52
3.2.1 Justification of the methodological choice 54
3.2.2 Limitations of the research design 55
3.3 Setting and ICU staffing model 56
3.4 Sampling and recruitment 57
3.4.1 Sampling and recruitment of ICU patients and families 57
3.4.1.1 Sample size 61
3.4.2 Sampling and recruitment of ICU nurses 63
3.5 Instruments 63
3.5.1 Instruments to measure family outcomes 67
3.5.1.1 CCFNI and NMI 67
3.5.1.2 Family Feedback Survey 70
3.5.1.3 Nurses' focus groups 70

3.5.2 Instrument to measure nurses' outcomes....72
3.5.2.1 Modified Nursing Stress Scale....72
3.5.3 Instrument to measure patient and the healthcare system outcomes....75
3.5.3.1 Muscle Measurement....75
3.5.3.2 Patient and healthcare system outcomes....76
3.6 Study phases....76
3.6.1 Scoping....77
3.6.1.1 Ethics application....79
3.6.1.2 Data management and confidentiality....79
3.6.1.3 Information sheets and consent forms....80
3.6.2 Process....81
3.6.2.1 Passive exercises: and education of nurses and families on how to deliver them....81
3.6.3 Outcome....82
3.7 Conclusion....82
Chapter 4 Assessment of the impact on the family, patient and healthcare system....84
4.1 Introduction....84
4.2 Focus upon the family, patient and healthcare system....84
4.3 Establishing the participants cohort....85
4.4 Patient and family demographics....87
4.5 Results and analysis of the Critical Care Family Needs Inventory....90
4.5.1 Comparison of the CCFNI results between the active unit families pre-test to active unit nurses pre- and post-test....91
4.5.1.1 Active unit pre-test....93
4.5.1.2 Active unit post-test....94
4.5.2 Comparison of the CCFNI results between the control unit families pre-test to control unit nurses pre- and post-test....94
4.5.2.1 Control unit pre-test....97
4.5.2.2 Control unit post-test....98
4.5.3 Comparison of the CCFNI results between the nurses of the active and control units pre- and post-test....99
4.5.3.1 Active unit....99
4.5.3.2 Control unit....100

4.5.4 Comparison of the CCFNI results between the nurses of the active and control units pre- to post-test 102
4.5.5 Summary of the analysis and results of the CCFNI 102
4.6 Results and analysis of the Needs Met Inventory 104
4.6.1. Active unit 105
4.6.2. Control unit 107
4.6.3 Summary 110
4.7 Results and analysis of the Family Feedback Survey 111
4.8 Results and analysis of the clinical and healthcare outcomes 112
4.8.1 Muscle measurements 113
4.8.2 Ventilator hours, length of stay and mortality 114
4.9 Conclusion 116
Chapter 5 The experiences of the nurses 118
5.1 Introduction 118
5.2 Focus on the experiences of the nurses 118
5.3 Survey distribution process 119
5.4 Demographics 120
5.4.1 Years nursing 120
5.4.2 Years nursing in ICU 121
5.5 Modified Nursing Stress Scale 122
5.5.1 Analysis of the mNSS results pre-test 122
5.5.1.1 Highest stressors 122
5.5.1.2 Lowest stressors 125
5.5.1.3 Difference in perception of stressors between the active and control unit nurses 125
5.5.2 Analysis of the mNSS results post-test 125
5.5.3 Comparison of the results of the mNSS between the nurses of the active and control units 126
5.5.4 Comparison of the results of the mNSS by years of nursing experience and years nursing in ICU 127
5.6 Conclusion 129
Chapter 6 Perceptions of the nurses 131
6.1 Introduction 131
6.2 Demographics of the focus groups 132

6.2.1 Active unit 133
6.2.2 Control unit 133
6.2.3 Managers and educators 133
6.2.4 Summary of demographics 134
6. 3 Focus group findings 134
6.3.1 Families 136
6.3.1.1 Assisting with care 137
6.3.1.2 Satisfaction and reassurance 139
6.3.1.3 Communication and relationships 141
6.3.1.4 Death and dying 142
6.3.2 Patient 143
6.3.3 Nurses 144
6.4 Conclusion 145
Chapter 7 Discussion 147
7.1 Introduction 147
7.2 Study contextualised with previous research 148
7.3 Summary of key findings 157
7.4 Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for families? 159
7.4.1 Identified needs and needs met 160
7.4.1.1 CCFNI 160
Families compared to nurses pre-test 161
Families compared to nurses post-test 161
7.4.1.2 CCFNI compared to NMI 162
7.4.2 Needs not met 163
7.4.3 Family Feedback Survey 166
7.4.4 Focus groups 166
7.5 Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for nurses? 168
7.5.1 Nurses demographics 169
7.5.2 Nursing stress 169
7.6 Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for patients and the healthcare system? 174

7.6.1 Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for patients? 174
7.6.2 Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for the healthcare system? 176
7.5.3 Focus groups 178
7.7 Analysis considering the theoretical framework 178
7.7.1 Outcome for families 180
7.7.2 Outcome for nurses 184
7.7.3 Outcomes for the patient 185
7.7.4 Outcomes for the healthcare system 186
7.8 Conclusion 187
Chapter 8 Conclusion 189
8.1 Unique contributions of this thesis 189
8.2 Summary of the study findings 190
8.2.1 Concise answers to the research questions 191
8.3 Research limitations 193
8.4 Directions for future research and application to clinical practice 194
8.4.1 Research 194
8.4.2 Application to clinical practice 195
8.5 Conclusion 196
References 197
Appendices 214
Appendix 1: Letter to staff 214
Appendix 2: Patient screening tool 215
Appendix 3: Information pamphlet for family participants-Active Unit 216
Appendix 4: Information pamphlet for family participants Control Unit 218
Appendix 5: Family consent form 220
Appendix 6: Passive exercises pamphlet 221
Appendix 7: Passive limb exercises record 226
Appendix 8: Nurses' focus group participation letter 227
Appendix 9: Nurses' focus group participant consent form 229
Appendix 10: Focus group questions 230
Appendix 11: 30-item CCFNI and NMI 231

Appendix 12: Family assisted passive exercise instrument (excluding CCFNI, NMI and FSS data) an example of one patient's de-identified data 233
Appendix 13: Pre-test distribution of the CCFNI data in the active unit (family) 234
Appendix 14: Post-test distribution of the NMI data in the active unit 235
Appendix 15: Family Feedback Survey distribution analysis active unit 237
Appendix 16: Pre-test distribution of the CCFNI data in the control unit (family) 238
Appendix 17: Post-test distribution of the NMI data in the control unit (family) 239
Appendix 18: Family feedback distribution control unit (family) 241
Appendix 19: Modified Nursing Stress Scale instrument 243
Appendix 20: Cronbach's alpha: pre-test complete results 246
Appendix 21: Cronbach's alpha: post-test complete results 247

List of tables

Table 2. 1: Scoping review 19
Table 2. 2: Agencies and health policy documents and websites reviewed 19
Table 2. 3: Literature focus presented by themes 20
Table 2. 4: Definitions and dimensions of PFCC from key agencies 28
Table 2. 5: Elements of the Structure, Process Outcome quality model 44
Table 2. 6: Picker Institute's eight principles of patient-centred care 45
Table 2. 7: McCormack and McCance's person-centred framework 47

Table 3. 1: Inclusion and exclusion criteria for the patient 57
Table 3. 2: Sample size determinant using the National Statistical Service's sample size calculator 62
Table 3. 3: Research questions and instruments used to answer them 64
Table 3. 4: Pre-test Cronbach's alpha of the study specific items of mNSS 73
Table 3. 5: Post-test Cronbach's alpha of the study specific items of mNSS 73
Table 3. 6: mNSS factors and items maximum scores 74
Table 3. 7: Kotter's eight-step process for implementing change 77
Table 3. 8: List of information letters and pamphlets 80

Table 4. 1: Instruments used to address the research questions 84
Table 4. 2: Age of all enrolled patients 87
Table 4. 3: Age of patients lost to follow-up 87
Table 4. 4: Age of remaining patients 88
Table 4. 5: Demographics of all enrolled patients and their families 88
Table 4. 6: Demographics of those patients and their families lost to follow-up 89

Table 4. 7: Demographics of the remaining patients and their families 89
Table 4. 8: Comparison of all enrolled, those lost to follow-up and final cohort of patients and families 89
Table 4. 9: Analysis of the CCFNI 90
Table 4. 10: Means, significance ratings of perceived importance of needs Active Unit: families pre-test to the nurses' pre- and post- test 92
Table 4. 11: Means and significance ratings of the domains: active unit families pre-test compared to active unit nurses pre- and post- test 93
Table 4. 12: Means, significance ratings of perceived importance of needs control unit: families pre-test to the nurses' pre- and post- test 96
Table 4. 13: Means and significance of the domains: control unit families pre-test compared to control unit nurses pre- and post- test 97
Table 4. 14: Means and significance of individual items and domains of CCFNI comparison pre- and post-test for nurses of the active unit 100
Table 4. 15: Means and significance ratings of perceived importance of families' needs comparison pre- and post-study period for nurses of the control unit 101
Table 4. 16: Comparison of the CCFNI between the active and control unit nurses pre- to post-test 102
Table 4. 17: Summary of the analysis and results of the CCFNI 102
Table 4. 18: Analysis of the NMI 104
Table 4. 19: CCFNI and NMI paired analysis of means significance ratings for families of the active unit 106
Table 4. 20: CCFNI and NMI paired analysis of means and significance by domains for families of the active unit 107
Table 4. 21: CCFNI and NMI paired analysis of means and significance ratings for families of the control unit 109
Table 4. 22: CCFNI and NMI paired analysis of means and significance by domains for families of the control unit 110
Table 4. 23: Summary of the analysis and results of the CCFNI compared to the NMI for the families of theactive and control units 111
Table 4. 24: Comparison of the results of the FFS between the active and control unit families 112
Table 4. 25: Paired comparison between the patients' first and second muscle measurements 113
Table 4. 26: Comparison of change value of the mean of patients' muscle measurements 114
Table 4. 27: Summary of the analysis and results of the patients' muscle measurements 114
Table 4. 28: Clinical outcomes and healthcare efficiency measurements for all enrolled patients 115
Table 4. 29: Clinical outcomes and healthcare efficiency measurements of patients lost to follow-up 115
Table 4. 30: Clinical outcomes and healthcare efficiency measurements of remaining patients 116
Table 4. 31: Mortality of patients 116

Table 5. 1: Measurement instrument used to address the research question 118
Table 5. 2: Years nursing.....120
Table 5. 3: Years nursing in ICU.....121
Table 5. 4: mNSS comparison of mean results and significance.....123
Table 5. 5: Active unit mNSS results by factors pre- to post test.....126
Table 5. 6: Control unit mNSS results by factors.....126
Table 5. 7: Mean results of mNSS from all respondents.....127
Table 5. 8: Mean results of mNSS by years of nursing.....127
Table 5. 9: Mean results of mNSS by years of nursing in ICU.....128
Table 5. 10: The role of nursing experience: correlation analysis- active nad control units combined.....128
Table 5. 11: Summary of the analysis and results of the mNSS.....129

Table 6. 1: Method used to address the research questions.....132
Table 6. 2: Focus group demographics.....133

Table 7. 1: Comparative studies that used the CCFNI.....148
Table 7. 2: Summary of research study.....157
Table 7. 3: Comparative NSS studies.....170
Table 7. 4: Retrospective APACHE II Score on all enrolled patients.....175
Table 7. 5: The outcomes of PFCC principles.....181

List of figures

Figure 1.1: Aims of family assisted passive exercises on unconscious patients in ICU 9

Figure 2. 1: Screening process and outcome of the scoping review and iterative search of the literature 15
Figure 2. 2: SPO model as applied in the ICU context for this study.....45
Figure 2. 3: Theoretical framework for family assisted passive exercising in ICU 49

Figure 3. 1: Sequencing of the study 54
Figure 3. 2: Visual diagram of the study design.....54
Figure 3. 3: Flowchart to determine patient suitability for inclusion in the study.....59
Figure 3. 4: Instruments and timelines for families.....68
Figure 3. 5: Instruments and timelines for nurses.....74
Figure 3. 6: Instrument and timelines for patients and healthcare system.....75
Figure 3. 7: Study Phases.....77

Figure 4. 1: Flow diagram, establishing the participants' cohort 86
Figure 4. 2: Results of the FFS 112

Figure 5. 1 : Survey distribution process 119

Figure 6. 1: Focus group word-cloud 136

Figure 7. 1: Theoretical framework for family assisted passive exercising in ICU 179

Figure 8. 1: Outcomes of research 191

Presentations arising from this research

Dixon, J. (2014) ICU RPAH, Patient and family centred care project, reducing muscle wasting in unconscious patients*, The Pitch: Sydney Local Health District*, Sydney, Australia, 22nd August.
Dixon, J. (2016) Family assisted passive exercising in the intensive care unit, *Nursing and Midwifery Research Symposium: Sydney Local Health District*, Sydney, Australia, 23rd November.
Dixon, J. (2017) Family assisted passive exercising in the intensive care unit, *Research Week, University of Tasmania, Rozelle Campus*, Sydney, Australia, 5th September.
Dixon, J. (2017), Family assisted passive exercising in the intensive care unit, *International Society of Quality Assurance, Annual Conference*, London, England, 1st -5th October poster
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Glossary of terms

ABS: Australian Bureau of Statistics

ACCN: Australian College of Critical Care Nurses

AIHW: Australian Institute of Health and Welfare

ACSQHC: Australian Commission on Safety and Quality in Health Care

ACI: Agency for Clinical Innovation

ALS: Amyotrophic lateral sclerosis

APACHE: Acute Physiology, Age, Chronic Health Evaluation

BMI- Body mass index

CCFNI: Critical Care Family Needs Inventory

CEC: Clinical Excellence Commission

CIAP: Clinical Information Access Portal

CNC: Clinical nurse consultant

CNE: Clinical nurse educator

ECMO: Extra-corporeal membrane oxygenation

EMR: Electronic medical record

FAPEI: Family assisted passive exercise instrument

FCC: Family centred care

FFS: Family Feedback Survey

FFT: Friends and Family Test

FiO2: Fraction of inspired oxygen

GCS: Glasgow Coma Scale

HELP: Hospital end of life planning

HREC: Human Research Ethics Committee

ICCA: Intellispace Critical Care and Anaesthesia

ICU: Intensive care unit

ICUAW: Intensive care acquired weakness

IHI: Institute for Healthcare Improvement

IOM: Institute of Medicine

IPFCC: Institute for Patient and Family-Centered Care

ISHLD: Illawarra Shoalhaven Local Health District

Level III ICU: A tertiary referral unit for intensive care patients, that is capable of providing comprehensive critical care including complex multi-system life support for an indefinite period. Level III units should have a demonstrated commitment to academic education and

research. All patients admitted to the unit must be referred for management to the attending intensive care specialist (ANZ College of Intensive Care Medicine 2011).

LHD: Local Health District

MAP: Mean arterial pressure

MMT: Manual muscle test

NEMS: Neuromuscular electrical stimulation

NHS: National Health Service

NMI: Needs Met Inventory

NSQHS: National Safety and Quality Health Service

NSS: Nursing Stress Scale

NSW: New South Wales

NUM: Nursing unit manager

PCC: Patient centred care

PEEP: Positive end-expiratory pressure

PFCC: Patient and family centred care

P/F Ratio: Partial pressure to inspired oxygen

PIP: Patient information portal

REDCap: Research electronic data capture (REDCap is brought to you by the Clinical Research Centre at Sydney Local Health District).

RN: Registered nurse

RPAH: Royal Prince Alfred Hospital

SLHD: Sydney Local Health District

SpO2: peripheral capillary oxygen saturation

WHS: Workplace health and safety

Abstract

Background: Patients who have a critical illness and a protracted admission to an intensive care unit (ICU) are known to develop muscle weakness and wasting. This can lead to increased length of stay in both the ICU and the hospital, and rehabilitation can also be prolonged. Admission of a family member to an ICU places heavy stress on a family, whereby the ongoing effects for the family and patient can take years to resolve, if ever. In the context of the patient and family centred care (PFCC) movement, family involvement in patient care, as a means of improving both patient and family outcomes, has been studied across multiple clinical contexts. However, a gap in knowledge is the impact of family assisting with passive exercises of unconscious patients in the ICU.

Purpose: To investigate whether family assisted passive exercising of an unconscious patient can achieve better outcomes for the family, nurses, patient and healthcare system.

Research design: A prospective, comparative, interventional study. The study was conducted between May 2015 and May 2016. The setting was two general ICUs in a publicly funded tertiary and quaternary referral hospital in Sydney, Australia. One unit was deemed the active unit, where family members delivered the passive exercises to the patient. The second unit was the control unit, where the patients received standard care with the direct care nurses performing the passive exercises.

The quantitative approach was the dominant aspect of the study. Outcomes of family needs and satisfaction were measured by surveying the ICU families with the: 30-item Critical Care Family Needs Inventory (CCFNI) pre-test; and 30-item Needs Met Inventory (NMI) and, single item Family Feedback Survey (FFS) tool, post-test. The nurses were surveyed with the CCFNI pre- and post-test to assess their perception of family needs, and to ascertain if the intervention improved alignment between the nurses' and the families' perception of need. Outcomes for nurses' stress, and whether the intervention had any impact on these stressors, were measured using the modified Nursing Stress Scale (mNSS) pre- and post-test. The modification included four study specific questions in relation to teaching, talking and discussing clinical care with family members and delivering passive exercises to patients.

Muscle mass measurement was the major clinical outcome for the patient and was evaluated using ultrasound technology and a tape measure. Organisational and clinical factors were evaluated to ascertain outcomes for the patient and the healthcare system. Information that was extracted from the ICU electronic medical record (EMR) and entered into the study specific family assisted passive exercise instrument (FAPEI), for this purpose, included: demographics of the patient and the family member; patient mortality; the number of hours the patient received mechanical ventilation; and, ICU and hospital length of stay.

Three focus groups were conducted. Two groups were with nurses from the active and control units, and one with the ICU managers and educators. The focus groups triangulated the data obtained from the CCFNI, NMI, mNSS and FSS with professionals' perceptions of the impact of the study on the family, nurses, and patients.

The quantitative data were analysed using descriptive and inferential statistics. The qualitative data from the focus groups used inductive content analysis.

Results: In total 30 families and patients were initially enrolled into the study. After attrition 19 families and patients completed the study – 10 in the active unit and nine in the control unit.

Pre-test, both the active and the control units responses to the CCFNI showed that nurses did not rank family needs as highly as the families regarding assurance, information and proximity domains. Post-test, the nurses' perception was more aligned with that of family, with greater improvement in the active unit. The level of improvement in the active unit was unmatched in the control unit. The comparison of the results of the CCFNI pre-test to the NMI post-test completed by the families showed that needs were met more in the active unit. This result was not matched in the control unit.

The FSS was given a maximum score of 100, by five families in the active unit and four families in the control unit.

The mNSS was completed pre-test by a majority of nurses from the active unit (n= 45; 80%) and the control unit (n=55; 82%). Similarly, a majority of nurses completed survey post-test in both the active unit (n=40; 69%) and control unit (n=40; 85%). Pre-test the results of the

mNSS showed there was little difference between the units in regards to the highest and lowest scoring individual stressors. Both units scored the most stressful items from the death and dying and workload factors. Pre- to post-test there was greater improvement (a decrease) in the mean scores of these factors and the factor, conflict with other nurses, in the active unit. Again this was not matched in the control unit. The results across both units, demonstrated that there was a correlation between years of nursing experience and how stress was perceived.

In the outcome of muscle mass measurement, the study did not detect any change in the units due to the intervention. Clinical and organisational outcomes showed no discernible patterns that could be specifically attributed to the intervention.

The focus group nurses supported the importance of PFCC in the ICU. They highlighted the improvement in communication with families and the assurance for the families that resulted from the intervention.

Conclusion: Family assisted passive exercise, designed and implemented with the principles of PFCC can enhance family and nurses satisfaction in the ICU. The intervention improved communication between the nurses and families helping address family needs and reducing nurses' stress levels. However, the intervention did not prevent muscle wasting in ICU patients.

A significant study insight is that death and dying remains an on-going challenge in the ICU for both the families and the nurses. This has been identified as an area for service improvement and has led to enhanced communication training for the nurses. It has been identified that nursing stressors could be better managed when nurses interact with families, assisting them with passive exercises in ICU. This insight has not been previously reported.

This thesis has also made methodological contributions through modification of the NSS and the study specific theoretical framework, therefore, uniquely contributing to the knowledge of the understanding of PFCC.

In the outcome of muscle mass measurement, the study did not detect any change in the units due to the intervention. Clinical and organisational outcomes showed no discernible patterns that could be attributed to the intervention.

Chapter 1 Introduction

1.1 Introduction

This research was driven by organisational needs identified through a Sydney Local Health District (SLHD) patient and family centred care (PFCC) working party to implement, evaluate and embed PFCC in the intensive care units (ICUs) of a major teaching hospital in Sydney, Australia. This in turn was driven by both: the National Safety and Quality Health Service (NSQHS) Standards (Standard 2 -*Partnering with Consumers)* (ACSQHC 2017) and the NSW Clinical Excellence Commission (CEC) *Partnering with Patients Program.* The intention of which is to actively engage patients, family and carers as health team members with the aim of improving safety and quality in healthcare (CEC 2015).

This thesis examines the impact of a PFCC study, namely family assisted passive exercising of unconscious patients in the ICU, on the family, nurses, patients and healthcare system. This thesis seeks to examine if: family assisted passive exercises are as effective as the nurse assisted option; the intervention addressed family needs and nurses' stress and, if family assisted passive exercises are associated with any adverse outcomes. In investigating this issue, the study seeks to contribute both practical and theoretical insights to the field.

With this intention this chapter is structured as follows. The contextual background of ICU demand and justification for the study (section 1.2); that is, the number of patients admitted to the ICU in Australia annually and the implications of survival after a critical illness. It discusses the treatments for ICU acquired weakness (ICUAW), and how passive exercising may be a way of preventing or arresting it. The concept of family assisting with the passive exercising of their relative and the impact then, on the family, nurses, patient and healthcare system are presented. The statement of the problem is presented with three patient vignettes to set the scene for this research (section 1.3) and how this informed the research questions (section 1.4). The study specific theoretical framework (section 1.5) and the research method (section 1.6) follow; and then the study setting and participants are presented (section 1.7). The chapter concludes with outlining the thesis structure (section 1.8).

1.2 Background

1.2.1 ICU admissions and survival implications

In Australian, public hospitals, in 2015-16, approximately 104,000 patients were admitted to ICUs. In total, these patients spent a combined 9.7 million hours in the ICUs, of which 3.7 million hours (39,000 patients) required continues mechanical ventilation. The survival rate for this cohort of patients was approximately 87% (AIHW 2017).

Positively, the number of patients surviving an ICU admission is increasing (Turnbull, Rabiee & Davis 2016). However, an acute episode of critical illness and subsequent survival can place an enormous burden on the patient, their families and the healthcare system (Callahan & Supinski 2013; Kress & Herridge 2012; Marti et al. 2016; Morris et al. 2008; Schweickert et al. 2009). For the family, there may be financial hardship, caregiver burnout or other stressors associated with having a family member in ICU (Henneman & Cardin 2002; Kress & Herridge 2012; Marti et al. 2016; Needham et al. 2012). For the healthcare system, there can be the costs associated with long term recovery and rehabilitation (Kress & Herridge 2012; Marti et al. 2016). More importantly for the patient, this can be in the form of physical, mental health or cognitive sequelae (Turnbull, Rabiee & Davis 2016).

It has been identified that six months after discharge from an ICU, that survivors often have diminished health-related quality of life (McKinley et al. 2016); this is in relation to sleep, depression and stress. Longer term, research by Cuthbertson et al. 2010 concluded that, intensive care unit admissions are associated with: a high mortality and morbidity, a poor physical quality of life and a low quality adjusted life years gained. This is in comparison to the general population for five years after discharge.

It is known that patients that survive a protracted ICU admission suffer muscle wasting and weakness, known as ICUAW (Herridge 2009; Jolley, Bunnell & Hough 2016; Kress & Hall 2014; Morris et al. 2008; Winkelman et al. 2012; Young 2009). ICUAW can be caused by: loss of mechanical loading due to physical inactivity, bed rest, or immobilisation; medications such as steroids, vasoactive, sedatives and analgesia; or, disease processes such as sepsis (Chambers, Moylan & Reid 2009; Fan et al. 2014; Schweickert et al. 2009; Wolfe et al. 2018). This in turn can contribute to prolonged mechanical ventilation, increased length of ICU and hospital stay, and increased mortality and morbidity (Callahan & Supinski 2013;

Cuthbertson et al.2010; Fan et al. 2014; Jolley, Bunnell & Hough 2016; Schweickert et al. 2009).

Despite the knowledge about and negative consequences of the development of ICUAW in patients, much remains to be understood about its incidence, causes, prevention and treatment (Denehy et al. 2013; Griffiths & Hall 2010; Jolley, Bunnell & Hough 2016).

1.2.2 Treatments for ICUAW

There have been a number of treatments that have been trialed to try and prevent ICUAW. Some of these treatments include: early mobilisation of patients while they are still receiving mechanical ventilation (Amidei & Sole 2013; Engel et al. 2013; Green et al. 2016; Winkelman et al. 2012); cycle ergometers (Burtin et al. 2009; Camargo Pires-Neto et al. 2013; Nickels et al. 2017); neuromuscular electrical stimulation (Kho et al. 2012; Kho et al. 2016); physical therapy (Green et al. 2016; Morris et al. 2008; Morris 2008); and, passive exercising (Green et al. 2016; Wiles & Stiller 2010).

1.2.2.1 Passive exercises

Of these, passive exercising is standard care delivered by physiotherapists and nurses to ICU patients, to maintain joint range and prevent soft tissue contractures (Green et al. 2016; Wiles & Stiller 2010). The efficacy of these exercises has never been conclusively demonstrated or verified as a way to prevent ICUAW (Berney, Haines & Denehy 2012; Hodgson & Tipping 2017; Wiles & Stiller 2010) or to address family needs (Baning 2012; Goldfarb et al. 2017). This is a significant gap in knowledge that could suggest a negative impact upon the provision of high quality patient care.

The exercises and exercise regime to be used in this study, were based on *Passive and resistive range of motion exercises* (ALS 2004) and previous ICU research involving early mobility therapy of acute respiratory failure patients (Morris et al. 2008).

1.2.3 Needs of ICU families

For the families of patients with an acute, and often unexpected critical illness, the ICU environment is complex and stressful to navigate, when they are at their most vulnerable (Bailey et al. 2009; Scott, Thomson & Shepherd 2019). There has been extensive research that has identified that these families have specific needs that will help them cope with this

stressful situation (Azoulay et al. 2003; Bailey et al. 2009; Kinrade, Jackson & Tomnay 2010; Leske 2002; Maxwell, Stuenkel & Saylor 2007; Molter 1979; O'Neill-Norris & Grove 1986; Wong et al. 2015).

Molter's (1979) seminal work led to the development of the Critical Care Family Needs Inventory (CCFNI). This assessment instrument has been used along with the Needs Met Inventory (NMI) instrument (Bailey et al. 2009; Nolen & Warren 2014; Olding et al. 2016; Warren 1994), to identify what families perceive as their needs and whether they are met in the ICU. By meeting the needs of family members it has been reported that their stress levels can be reduced (Bailey et al. 2009; Leske 1991; Molter 1979; Nolen & Warren 2014; Olding et al. 2016; Warren 1994). Conversely, when family members needs are not met, then they may not be as available for their relative (Nolen & Warren 2014).

One way to help address the needs of families is by having them participate in patient care (Al-Mutair et al. 2013; Azoulay et al. 2003; Kean & Mitchell 2014; Olding et al. 2016; Rukstele & Gagnon 2013). Family participation in patient care has been used for many years in palliative care, gerontology and paediatric units, but it has been identified that further work is needed to integrate such an approach in adult ICUs (ACSQHC 2010; Hardin 2012; Hetland et al. 2017). Although there have been previous studies with ICU families participating with care (Al-Mutair et al. 2013; Azoulay et al. 2003; Bishop, Walker & Spivak 2013; Garrouste-Orgeas et al. 2010; Olding et al. 2016; Rukstele & Gagnon 2013), there was no literature identified that included family assisting with passive exercises. This is an important gap in the knowledge that warrants investigation to improve patient care and outcomes.

1.2.4 Workplace stressors for ICU nurses

Workplace stressors of ICU nurses have been widely documented (Gray-Toft & Anderson 1981b; Hayes, Douglas & Bonner 2013; Healy & McKay 2000; Lim, Bogossian & Ahern 2010; van Mol et al. 2015). These stressors are variable and include such factors as: workload, the death of patients, conflict with peers or other colleagues, not being adequately prepared to work in the ICU environment, uncertainty in regards to treatment, and lack of support to do their job (Gray-Toft & Anderson 1981b; van Mol et al. 2015; Young 2009).

It has been identified that increased stress levels for nurses, can ultimately lead to burnout (Craigie et al. 2016; Hegney et al. 2014; Leiter & Maslach 2016) and compassion fatigue

(Kompanje, Piers & Benoit 2013; van Mol et al. 2015). There is a perception that burnout and compassion fatigue is more common in high pressured environments, such as ICU with acutely unwell patients and distressed family members (Embriaco et al. 2007; Maslach & Jackson 1981; Moss, Nordon-Craft & Malone 2016; Poncet et al. 2007; Todaro-Franceschi 2013; van Mol et al. 2015). This has implications beyond the immediate staff member providing care. The broader impact is: that there may be a decrease in productivity, an increase in absenteeism and staff turnover (Luxford & Newell 2015; Moola, Ehlers & Hattingh 2008); as well as a decrease in quality of patient care and poor communication with families (Cimiotti et al. 2012; Hall et al. 2016; Shanafelt et al. 2002; Wallace, Lemaire & Ghalis 2009). These stressors can also impact on the effectiveness of implementing and sustaining PFCC. Investigating the impact of stress, on nurses in the ICU setting is an important contribution to the knowledge base to improve the overall patient care processes.

1.2.5 Healthcare system

Estimates around the world are that ICU beds take up approximately 20% of a hospital budget (Berney, Haines & Denehy 2012). The estimated total annual operational cost for ICU care in Australia was $2119 million, about 0.15% of gross domestic product (GDP) and 1.4% of total health care costs (Hicks et al. 2019). There are a number of variables that account for the overall cost including: case-mix of patients, occupancy rate of the unit, staff composition and variations in medical practice (Marti et al. 2016; Tan et al. 2012). However, there is consensus that the main cost is labour (Negrini et al. 2006; Schultz et al. 2017; Tan et al. 2012) and most recently in Australia, this was estimated at approximately 80% (Hicks et al. 2019).

The first day in an ICU is approximately four times as expensive, and other ICU days are approximately three times as expensive, as non-ICU hospital days (Page, Barnett & Graves 2017; Pastores, Dakwar & Halpern 2012; Rapoport et al. 2003; Unroe et al. 2010). The cost of a bed in a tertiary referral Australian ICU has been estimated on average, at $2670 per day, and a total stay per patient of $9852 (McLaws & Jarvis 2014; Rechner & Lipman 2005). This study therefore, wanted to examine whether the intervention of family assisted passive exercises could have any impact on reducing ventilator hours and length of stay in the ICU and the hospital. These were the identified measures of efficiency for this study.

The findings from this study will add to the body of knowledge in relation to PFCC. The knowledge derived will benefit not only the ICU at the study site, but will be transferable to other units within the hospital, the local health district (LHD), and other hospitals nationally and internationally.

1.3 Statement of the problem

The previous PFCC studies with families participating in care of their relative have left an important gap in the knowledge, about the impact of an ICU intervention aimed at meeting family member's needs (Baning 2012; Goldfarb et al. 2017; Nolen & Warren 2014). In particular, ICU families assisting with passive exercising of their relative and the impact that this would have on: the families, nurses, patients and healthcare system. This study is significant as it will examine whether ICU families assisting with passive exercising can address family needs and improve their satisfaction with care; address the needs of nurses and reduce their stress levels. Additionally, and as importantly, whether the intervention can prevent or diminish ICUAW and, therefore, improve outcomes for the patient and the healthcare system.

The following three vignettes have been included to frame and support the beneficence of this PFCC study. Each of the patient stories helps give insight into the study. They set the scene of this PFCC study and demonstrate what went well and, also, that, which went not so well. They also demonstrate the severity of the illnesses for this cohort of patients, and the willingness of the families to partner with the nurses' in delivering care to their relatives.

1.3.1 Patient vignettes

Vignette one:

Mr. A. had an out of hospital cardiac arrest and was admitted to the ICU active unit after being transferred from another hospital within Sydney. In line with the results of the demographics Mr. A could be considered our "average" patient. He was male, 55 years old and his family member was his wife. He was born overseas and was working prior to this catastrophic event. Mr. A's wife enrolled for the study and was actively involved in her husband's exercises and care. Mr. A, was mechanically ventilated for 241 hours and stayed in the ICU for 45 days and in the hospital for 55 days. Mr. A. had his upper and lower limbs measured three times while he was in the ICU; these measurements demonstrated an average muscle reduction (in centimetres) of 10%. The nurses that were involved with Mr. A.'s care confirmed that they developed a relationship with Mrs. A., who was grateful to be included in her husband's care; and that Mr. A. when he recovered expressed his gratitude for the care that he had received.

Vignette two:

Mr. B. was an 83-year-old man from the United Kingdom who was on holiday, on a cruise ship around Noumea with his wife, when he became unwell with pancreatitis. Due to bad weather he was managed medically on board the cruise ship for five days. Eventually he was airlifted from the cruise ship, to Australia, for tertiary level medical care. On arrival at the ICU control unit Mr. B. was extremely unwell. His wife was in attendance from his admission and was keen to be involved with her husband's care, even wanting to participate with the exercises. He was mechanically ventilated for 11 days and spent 18 days in the ICU. He had his upper and lower limbs measured three times while he was in the ICU; these measurements demonstrated an average muscle reduction (in centimetres) of 3%. Mr. B made a slight improvement and was discharged from the ICU to a ward bed. However, he had to be readmitted to the ICU. In total he was in the hospital for 68 days when he finally succumbed to the illness and died.

Vignette three:

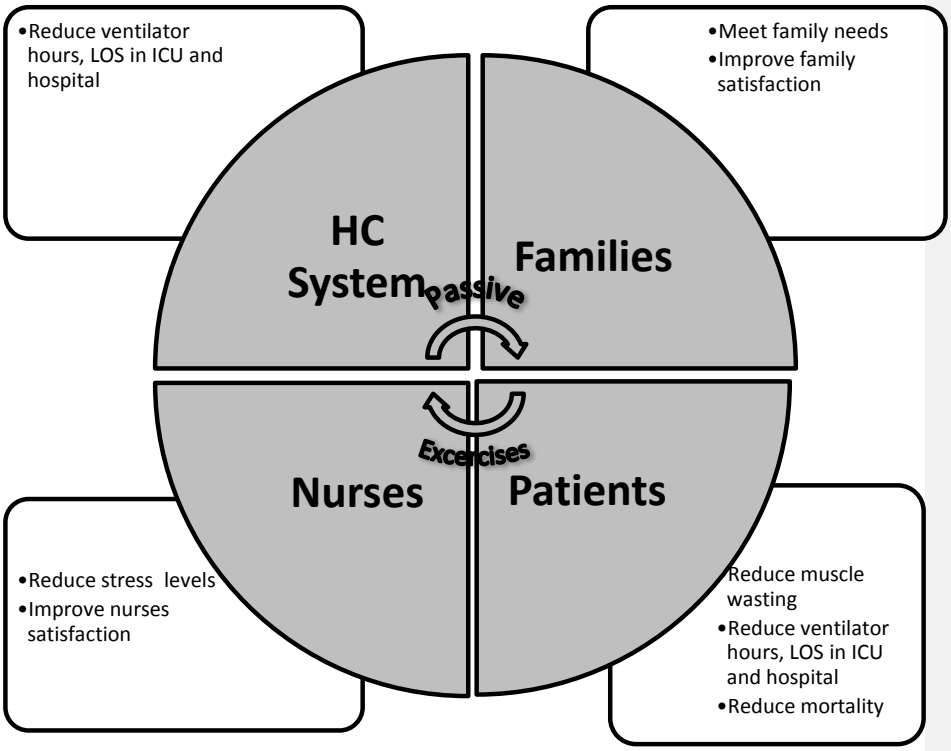
Mr. C. was a 21-year-old New Zealand born man who had recently moved to Australia to complete a Masters' degree at an Australian University. Mr. C. became unwell with meningococcal disease and was admitted to the ICU control unit. Even though he was extremely unwell, his parents who were both doctors enrolled in the study. Following enrolment into the study, Mr. C. had to have both of his legs amputated above the knee and both his arms amputated below the elbow. Due to the severity of the disease and the resulting skin loss Mr. C. was transferred to another facility for specialist treatment. He was lost to follow-up. However on his return to New Zealand his parents contacted the ICU and forwarded a link to a documentary that was made about their son. What was evident from the documentary was the level of muscle wasting that had occurred while Mr. C. was in ICU and the slow road to recovery to regain muscle bulk in what remained of his limbs. Mr. C. continues to make a remarkable recovery and with adapted prosthetic limbs has resumed playing the guitar.

1.4 Research questions

The aims of the research are demonstrated in Figure 1.1 and led to the research questions.

Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for the families?
Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for the nurses?
Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for the patients?
Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for the healthcare system?

Figure 1.1: Aims of family assisted passive exercises on unconscious patients in ICU



1.5 Theoretical framework

To examine the impact of family assisted passive exercising of unconscious relatives in the ICU, on the families, nurses, patients and the healthcare system, required the development of a unique theoretical framework to answer the research questions. The theoretical framework developed for this study will be discussed fully in the literature review chapter. In summary, the framework melded three frameworks. First, the overarching framework, used a quality structure, process and outcome (SPO) model, to drive the improvement process (Donabedian 1988). This was integrated with the principles of PFCC, developed by the Picker Institute, that have been adopted in the local setting by the Australian Commission on Quality and Safety in Health Care (ACSQHC 2010, 2017; Picker Institute 2008). Finally, elements of the person-centred nursing framework, developed by McCormack and McCance (2006), were used to extend and compliment the study focus.

1.6 Research method

After reviewing PFCC studies in the literature the following research method was developed for this study. The research used a prospective (Azoulay et al. 2003; Mitchell et al. 2016), comparative (Baning 2012; O'Neill-Norris & Grove 1986; Rippin et al. 2015), interventional (Baning 2012) design. At commencement of the study little was known about intensive care unit acquired weakness and its relationship with PFCC. Hence, an explanatory design was used to investigate a significant practice problem in the ICU context.

Data were collected both quantitatively and qualitatively (Burr 1998; Fereday 2006; Mitchell et al. 2016). The quantitative data were the dominant measures of outcome, including: surveys completed by the family and nurses; measurement of the patients' muscles; and information extracted from the patients' electronic medical record (EMR). The qualitative data were provided by focus groups held with the direct care ICU nurses (Bloomer et al. 2013; Burr 1998; Onwuegbuzie et al. 2009). Comparisons were made between the data from the participants of the family, patients and nurses from both the active and control units before and after the intervention of passive exercises. Detail of the research design and justification of the methodological choice is discussed further in Chapter 3.

1.7 Setting and participants

This study took place in two of four ICUs, that combined have 48 beds, at Royal Prince Alfred Hospital (RPA), Sydney, Australia. The two adult, level III ICUs, are part of a publically funded 920 bed teaching hospital in the inner-west of Sydney (RPAH Strategic Plan 2013-18). The ICUs provide both medical and surgical services to the local community as well as tertiary and quaternary services to NSW, interstate and overseas patients. Data, from 2013, were extracted from the ICU EMR, which showed that in total 3456 patients were admitted to the four units. Of these patients 225 died in the ICU and 119 survived ICU but died in the hospital, giving a survival rate of 90% for the study site.

In one ICU, the family participated in the passive exercising of their relative and will be referred to in the thesis as the active unit. In the other ICU, the patients received standard care from the nurses and will be referred to in the thesis as the control unit.

Enrolment of participating patients and family members was from May 2015 to May 2016. Patients were screened on admission and then daily by one of the research team in both the

active and control units to ascertain whether they met the selection criteria. The selection criteria and process are outlined in Chapter 3.

Families that consented to participate in the study completed the CCFNI survey at enrolment (pre-test), and the NMI and Family Feedback Survey (FFS) when their family member was discharged (post-test) from the ICU. Data were collected from the EMR for patient and family demographics and information that determined patient and healthcare outcomes post-test. The comprehensive details are outlined in Chapter 3.

All the nurses from the active and control units were invited to complete the modified Nursing Stress Scale (mNSS) and CCFNI survey tools, in May 2015 pre-test, and May 2016 post-test. The demographics of years nursing and years nursing in ICU were also collected at this time. Three focus groups were held with the nurses post-test. The purpose of the focus groups was to triangulate the data from the quantitative instruments. The underlying logic of mixing the data sources is that neither quantitative nor qualitative methods are sufficient in themselves to capture the trends and details to answer the research question (Mitchell et al. 2016; Onwuegbuzie & Collins 2007).

1.8 Outline of the thesis

This thesis is presented over eight chapters, commencing with this overview of ICUAW and the significance of this PFCC intervention of family assisted passive exercising of unconscious patients on: family, nurses, patients and the healthcare system. The purpose of the research has been articulated, the research questions and theoretical framework presented, along with the study setting and participants.

Chapter 2 presents the literature review and outlines the search strategy. It explores the PFCC literature and the implications of PFCC for: the families, nurses, patient and the healthcare system. The analysis identifies gaps in the literature that leads to the research questions, and the significance and justification of the research, as well as discussing the limitations of the review. It concludes by presenting the unique theoretical framework developed and used in this study.

Chapter 3 outlines the research design. It discusses the justification for the design as well as the limitations in the design chosen. It expands on the setting for the research and the sampling and recruitment of the study participants. The instruments used to measure the outcomes for the families, nurses, patients and healthcare system are presented and their relevance to the theoretical framework. The chapter concludes by describing the three study phases, of scoping, process and outcome. The scoping phase included the formation of the working party, ethics application and development of exercises and information sheets for all the participants. The process phase included the intervention of the passive exercises. Then, finally the outcome phase comprised of the data collection and analysis to ascertain what impact the intervention had on the families, nurses, patients and healthcare system.

Chapter 4 presents an overview of the instruments used to answer the research questions for the families, patients and the healthcare system. This is followed by a section that explains the establishment of the family and patient participant cohorts and the demographics of these two groups. The results of the instruments follow and include: the CCFNI completed by the families and nurses of both the active and control units; the NMI completed by the families from the active and control units and the FSS completed by the families of the active and control units. The clinical outcomes for the patient and the healthcare system are presented in tandem, and include: the patients', muscle measurements; ventilator hours; length of stay in ICU and the hospital and mortality. The chapter concludes, by summarising the results for the families, patients and the healthcare system.

Chapter 5 focuses on the experiences of the nurses which were measured using the mNSS. This tool was used to examine, what workplace factors nurses found most and least stressful and whether the intervention of passive exercises affected these stressors. The chapter commences by outlining the distribution process of the mNSS to the nurses. This is followed by the demographics of the nurses, examining their years nursing and years nursing in ICU. The results of the mNSS completed by the nurses are examined by comparing: the individual units, pre- to post-test; the active to the control units and years of nursing to years working in ICU. The chapter concludes by summarising the nurses' results.

Chapter 6 presents the perception of the study by the nurses, obtained through the three focus groups. The chapter commences by presenting the demographics of each group, followed by

the focus group findings. The findings are thematically analysed and are separated into the elements of the families, patients and nurses.

Chapter 7 discusses the key findings from the research and places these findings against comparable research. It makes judgements as to what this research has discovered and how it has added to the body of knowledge.

Chapter 8 concludes the thesis by discussing the: unique contributions of the thesis; summary of the study findings and the answers to the research questions; research limitations and recommendations for future research and applications to clinical practice; and how the study has contributed to the knowledge.

1.9 Conclusion

This chapter has provided the background of ICUAW, the reason for the study and positioned this thesis within the context of PFCC. It has discussed the treatments for ICUAW and how passive exercising may be a way of preventing or arresting it. The concept of family assisting with the passive exercising, and the impact on the family, nurses, patient and healthcare system have been considered. The next chapter will present the literature in relation to PFCC in the ICU and the family, patient, nurses and healthcare system. The chapter concludes by presenting the theoretical framework.

Chapter 2 Literature review

2.1 Introduction

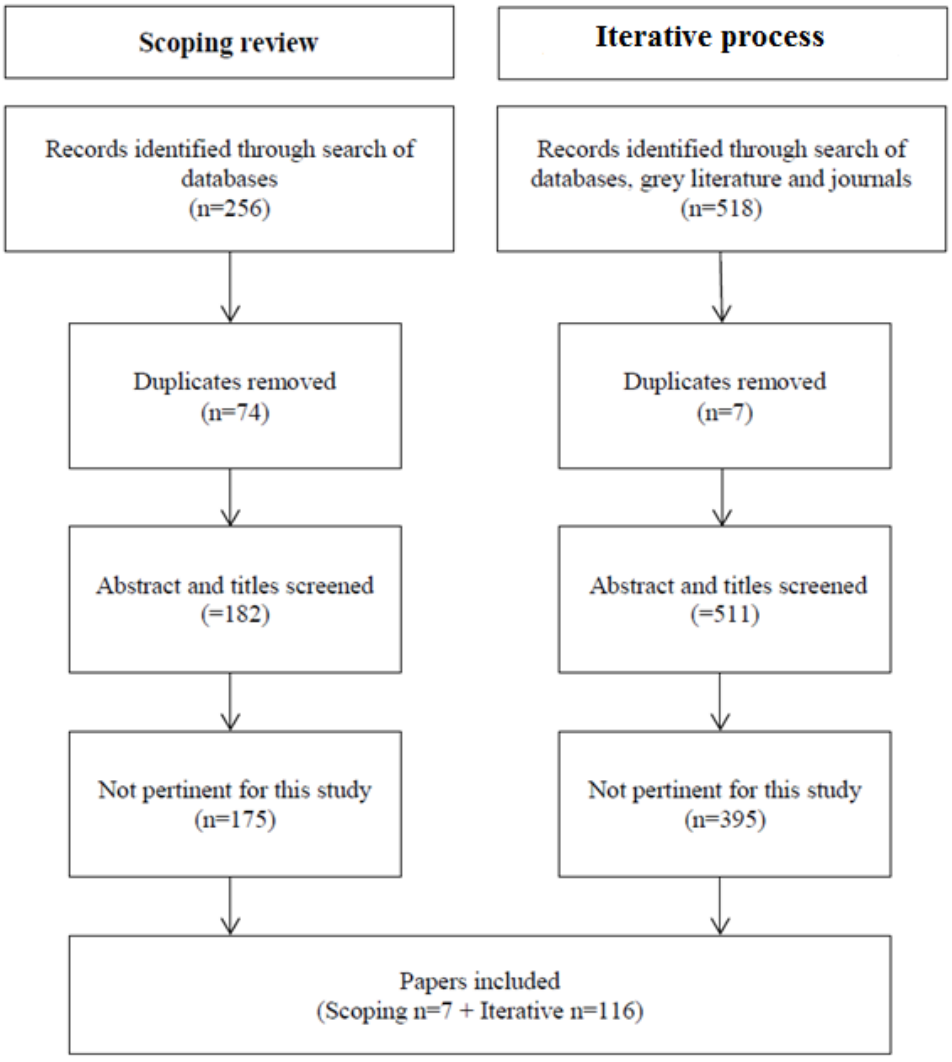
Chapter 1 presented an overview of the background and justification for the study. It discussed the treatments for ICUAW and how, passive exercising may be a way of preventing or arresting it. The concept of family assisting with the passive exercising and the impact of that on the families, nurses, patient and healthcare system, were considered. Building on this foundation, the purpose of this chapter is to identify and, then assess the literature in order to ground the study, both theoretically and empirically. In doing so, this enables articulation of the study questions that will guide the research.

The literature review uses a combination of a scoping and an iterative process to determine what has previously been studied. With this intention this chapter is structured as follows. First the search strategy is presented (section 2.2); this includes the scoping review of the literature, giving an explicit targeted structure defining themes (section 2.2.1); followed by an iterative search strategy of the literature, the focus of which is PFCC in ICU (section 2.2.2). This provides flexibility and defines the themes and identifies the categorised papers. This will be achieved by examining what has previously been studied in relation to family assisting with care in ICU with a focus on families assisting with passive exercising of their unconscious relatives. Additionally, consideration will be given to the implications of PFCC and families assisting with care on the families, nurses, patients and healthcare system. PFCC is defined (section 2.3) and then the implications of PFCC for families of patients in ICU, with a focus on how PFCC may address family needs and how families assisting with care can address those needs (section 2.4). The implications of PFCC for: ICU patients (section 2.5); ICU nurses with a focus on workplace stress and how PFCC may address this (section 2.6) and the healthcare system (section 2.7) are presented and discussed. The chapter concludes by presenting the strengths and limitations of the literature search and review (section 2.8); the research questions and the significance of the study (section 2.9) and the theoretical framework (section 2.10).

2.2 Search Strategy

The needs of the study setting initiated the search for policy and academic material at the intersection of three key topics: PFCC, adult ICU and passive exercise. Policy material and academic literature were identified through a combination of a scoping review (Constand et al. 2014;Curran et al. 2017;Olding et al.2016; Victoor et al. 2012) outlined in section 2.2.1; and an emergent, iterative search process (Debono, 2014; Greenfield et al. 2010) outlined in section 2.2.2. The screening process and outcome for both methods are presented in Figure 2.1.

Figure 2. 1: Screening process and outcome of the scoping review and iterative search of the literature



It is recognised that there are possible limitations to this review process in regards to the quality of the literature reviewed but this combined approach was used to garner the breadth of knowledge on the subject matter as defined by the research questions (Victoor, et al. 2012; Curran et al. 2017).

2.2.1 Scoping review

Scoping reviews are an exploratory review methodology used to rapidly map the literature on a well-defined topic (Olding et al. 2016). The scoping review was used, as at the time of the study a traditional systematic review did not provide the depth required for the elements under study and the complexity associated with PFCC and the multiple terms used for it. It was anticipated that a scoping review would encompass a broader focus (Contand et al. 2014; Curran et al. 2017; Olding et al. 2016, Victoor et al. 2012) that would reveal methodological and empirical gaps within the literature.

The search strategy presented in Figure 2.1 involved searching the electronic databases of Medline, Clinical Information Access Portal (CIAP) full text journals, Embase and Emcare for English language journal articles from 1995 to 2015 after the research questions had been determined.

The search terms were broad and included keywords of: *patient and family centred care/family centred care/person centred care/patient centred care/intensive care acquired weakness/ICUAW/intensive care unit acquired weakness/interventions/adult intensive care/exercise therapy and/or passive exercises/nursing stress and burnout/family needs/family satisfaction/family participation in care/length of stay ICU/ hospitalisation and/ or cost of patient admission/ respiration artificial and/or ventilator hours.*

This initial search yielded 1,503,754 citations across the four databases. The search was refined to look at a number of combinations of search terms as shown in Table 2.1. This gave a total of 256 articles across the four databases. All of the references were imported into Endnote and 74 duplicate citations were removed. This left 182 articles that were reviewed for relevance and contemporaneity with the CNC of ICU, by screening the title and abstract. From these, seven empirical studies remained that were pertinent to the study. These are shown in Table 2.3 with the studies identified through the iterative process.

Table 2. 1 Scoping review

	Search terms English Language	Databases				
		Medline 1996-2015	CIAP 1996-2015	Embase 1996-2015	Emcare 1995-2015	Total
1.	Patient and family centred care	162	355	225	100	842
2.	Family centred care	275	639	406	319	1639
3.	Person centred care	365	928	522	418	2233
4.	Patient centred care	1232	0	71280	7830	80342
5.	Intensive Care acquired weakness	4	7	23	7	41
6.	ICUAW	20	27	55	18	120
7.	Intensive care unit acquired weakness	51	35	107	64	257
8.	Interventions	223730	262505	303069	141682	930986
9.	Exercise therapy or passive exercises	20987	0	16313	7532	44832
10.	Nursing stress and burnout	32	95	41	24	192
11.	Family needs	380	1683	629	429	3121
12.	Family satisfaction	447	1383	850	454	3134
13.	Family participation in care	14	78	22	13	127
14.	Length of stay ICU	76	1823	211	47	2157
15.	Hospitalisation and/ or cost of patient admission	47970	0	198330	61551	307851
16.	Adult intensive care	297	418	421	261	1397
17.	Respiration artificial and/or ventilator hours	37292	0	55575	31616	124483
Total		333,334	269,976	648,079	252,365	1,503,754
Combination of search terms						
18.	1 & 16	3	10	5	3	21
19.	2 & 16	5	10	5	3	23
20.	3 & 16	0	0	0	0	0
21.	4 & 16	2	0	7	1	10
22.	5/6/7	0	0	0	0	0
23.	7 & 8	10	21	12	10	53
24.	7 & 8 & 16	0	0	0	0	0
25.	1&10	0	1	0	0	0
26.	10 & 16	1	1	1	1	4
27.	1 & 11 & 16	0	4	1	1	6
28.	1 &12 & 16	0	2	0	0	2
29.	1 & 13 & 16	0	4	1	1	6

	Search terms English Language	Databases				
		Medline 1996-2015	CIAP 1996-2015	Embase 1996-2015	Emcare 1995-2015	Total
30.	1 & 14 & 16	0	0	0	1	1
31.	1 & 15 & 16	0	0	0	0	0
32.	1 & 16 & 17	0	0	0	0	0
33.	16 & 17	23	0	59	47	129
34.	Total	44	53	91	68	256
35.	Removal of duplicates	5	19	25	25	74
36.	Records excluded	36	32	64	43	175
37.	Empirical studies	3	2	2	0	7

2.2.2 Iterative process

The second part of the search strategy as shown in Figure 2.1 was to gather more citations through health policy documents that guided practice in PFCC. Beginning with New South Wales (NSW) and Australia, an ad hoc search expanded to examine the health policy documents and websites of major quality improvement organisations in the United Kingdom (UK) and United States of America (USA). Search for health policy documents covered the period between years 2001 and 2015 and resulted in identifying 13 items as listed in Table 2.2. A review of these health policy documents and work of quality improvement organisations, led to both snowball and citation tracking methods, further extending the search for academic literature (Kitson et al. 2013).

The referenced studies and articles that guided the literature review are shown in Table 2.3 and are grouped by themes, which have been used as headings for sections in this chapter. This table gives a critical analysis review summary of the literature included presenting: the authors behind the study; when the study was published and where the study took place.

Table 2. 2: Agencies and health policy documents and websites reviewed

Country	Agency	Policy Document and Websites
Australia	Australian Commission on Safety and Quality in Health Care (ACSQHC)	Patient Centred Care, improving quality and safety by focusing care on patients and consumers (ACSQHC 2010)
	Clinical Excellence Commission (CEC)	Patient based care challenge http://www.cec.health.nsw.gov.au/echartbook/cec-indicators-intro-echartbook/patient-based-care (CEC 2015)
	Agency for Clinical Innovation (ACI)	Patient experience and consumer engagement. A framework for action (ACI 2015)
United Kingdom	The King's Fund	A High Performing NHS- A review of progress (1997-2010) (The King's Fund 2010) From vision to action. Making patient centred care a reality (The King's Fund 2012) Patients' experiences of using hospital services (The King's Fund 2015)
	The Health Foundation	Helping measure patient centred care (The Health Foundation 2014a) Person centred care from ideas to action (The Health Foundation 2014b) Measuring patient experience (The Health Foundation 2013)
	The Health Partnership	The state of play in person-centred care (The Health Partnership 2015)
United States	Institute of Medicine	Institute of Medicine Crossing the Quality Chasm (2001) A new health system for the 21st Century (Institute of Medicine (IOM) 2001)
	Institute for Patient and Family Centred Care	http://www.ipfcc.org/
	Picker Institute	Patient Centred Care Improvement Guide (Picker Institute 2008)

Table 2. 3: Literature focus presented by themes

Section	Critical analysis review summary	References
2.3 Defining PFCC	The references were sourced from English language, grey papers and peer reviewed journals, from Australia[1], UK[2], USA[3], Canada[4] and Europe[5.] The time period was from 1979-2015. After reviewing grey papers and journals in relation to PFCC, these articles and researchers were chosen for their expertise in the subject matter and to assist define PFCC. This included seminal work by Molter (1979), whose work had helped shape the PFCC landscape The inclusion of work from the UK and USA was because more research is being done there as they have a bigger health environment, in comparison to Australia. It also helped to gauge how Australia was faring with PFCC compared to these more populous countries.	(Molter 1979[3]) (Donabedian 1988[3]) (Institute of Medicine (IOM) 2001[3]) (Henneman & Cardin 2002[3]) (Azoulay et al. 2003[5]) (McCormack & McCance 2006[2]) (Maxwell, Stuenkel & Saylor 2007[3]) (Charmel & Frampton 2008[3]) (Picker Institute 2008[3]) (Watson & Frampton 2008[3]) (Davidson 2009[3]) (Johnson, Abraham & Shelton 2009[3]) (Mitchell et al. 2009[1]) (Mitchell & Chaboyer 2010[1]) (ACSQHC 2010[1]) (McCormack et al. 2010[1,2, 4]) (Proch 2011[3]) (ACSQHC 2012[1]) (Hardin 2012[3]) (Needham, Davidson & Cohen 2012[3]) (Kitson et al. 2013[1]) (Rukstele & Gagnon 2013[3]) (The Health Foundation 2014a[2]) (Rathert, Wyrwich & Boren 2012[3]) (CEC 2015[1]) (IHI 2015[3]) (Luxford & Newell 2015[1]) (The Health Partnership 2015[2])
2.4 Implications of PFCC for family of patients in ICU	The references were sourced from English language, grey papers and peer reviewed journals, from Australia[1], UK[2], USA[3], Canada[4] and Europe[5.] The time period was from 1979-2015. After reviewing grey papers and journals in relation to PFCC,	(Molter 1979[3]) (Azoulay et al. 2003[5]) (Coyer 2004[1]) (Lam & Beaulieu 2004[4]) (Eggenberger & Nelms 2007[3]) (Maxwell, Stuenkel & Saylor 2007[3]) (Picker Institute 2008[3]) (Bailey et al. 2009[4]) (Davidson 2009[3]) (Johnson, Abraham & Shelton 2009[3]) (Mitchell et al. 2009[1]) (ACSQHC 2010[1]) (Garrouste-Orgeas et

Section	Critical analysis review summary	References
	these articles and researchers were again chosen for their expertise in PFCC. The reason for choosing older references such as Molter (1979) was to compare her work, to more recent studies to see if and how PFCC had progressed up until recent years; given the changes to the healthcare system. Some of the articles referenced came from government (ACSQHC) grey papers and peak quality organisations such as The Picker Institute. These were considered appropriate given that this research was driven by organisational needs and these organisations are often instrumental in driving quality programs and research in the healthcare setting. Again it was considered appropriate to include work from the UK , USA, Canada and Europe to garner a broader understanding of the subject and to compare to the Australian setting.	al. 2010[5]) (Kinrade, Jackson & Tomnay 2010[1]) (Stricker et al. 2011[5]) (Cannon 2011[3]) (Rukstele & Gagnon 2013[3]) (Schleyer & Curtis 2013[3]) (Cappellini et al. 2014[5]) (Curtis, Sprung & Azoulay 2014[3]) (Nolen & Warren 2014[3]) (Wong et al. 2015[1])
2.4.1 Family needs in ICU	The references were sourced from English language, grey papers and peer reviewed journals, from Australia[1], UK[2], USA[3], Canada[4] and Europe[5]. The time period was from 1979-2015.These references were a combination of seminal work such as Molter (1979) and those that had built on her work such as O'Neill-Norris and Grove (1986) and Leske (1998). Then leading through to more contemporary studies, such as	(Molter 1979$_3$) (O'Neill-Norris & Grove 1986[3]) (Leske 1991[3]) (Warren 1994[3]) (Burr 1998[1]) (Leske 1998[3]) (Azoulay et al. 2003[5]) (Coyer 2004[1]) (Lam & Beaulieu 2004[4]) (Lee et al. 2007[3]) (Maxwell, Stuenkel & Saylor 2007[3]) (Morris et al. 2008[3]) (Picker Institute 2008[3]) (Bailey et al. 2009[4]) (Davidson 2009[3]) (Garrouste-Orgeas et al. 2010[5]) (Kinrade, Jackson & Tomnay 2010[1]) (Mitchell & Chaboyer 2010[1]) (Sheaffer 2010[3])

Section	Critical analysis review summary	References
	Maxwell, Stuenkel and Saylor (2007) and Kinrade, Jackson and Tomnay (2010) and looking at leading PFCC advocates such as The Picker Institute. The articles chosen consistently talked about the needs of families and referred to the domains of the CCFNI, including; proximity, assurance, information, comfort and support; and therefore of interest were those studies that had used the CCFNI and NMI, through to more recent times. Given the longevity of the tool and the changes to the healthcare system over time, it was of interest to see whether the tool still remained relevant.	(Cannon 2011[3]) (Ciufo, Hader & Holly 2011[3]) (Herridge 2011[4]) (Baning 2012[3]) (Davidson, Jones & Bienvenu 2012[2, 3]) (Obringer, Hilgenberg & Booker 2012[3]) (Al-Mutair et al. 2013[1]) (Callahan & Supinski 2013[3]) (Kitson et al. 2013[1]) (Adams et al. 2014[3]) (Cappellini et al. 2014[5]) (Davidson et al. 2014[3]) (Gentry et al. 2014[3]) (Riley et al. 2014[3]) (Trankle 2014[1]) (Wong et al. 2015[1]) (Kentish-Barnes et al. 2015[5,3])
2.4.2 Families assisting with care in ICU	The references were sourced from English language, grey papers and peer reviewed journals, from Australia[1], UK[2], USA[3], Canada[4] and Europe[5.] The time period was from 1979-2015 There was limited research found in the literature in relation to families assisting with care, at the time of the study commencing in 2015. Many of these articles were sourced from the government papers, in particular '*The state of play in person-centred care'* (The Health Partnership 2015) and the work of Al-Mutair et al. 2013 *Family needs and involvement in the intensive care unit: a literature review.* The latter led the researcher to the work of Australians such as, Kinrade, Jackson and Tomnay (2010) and Mitchell et al. (2009).	(Burr 1998[1]) (Henneman & Cardin 2002[3]) (Azoulay et al. 2003[5]) (McAdam, Arai & Puntillo 2008[3]) (Casarini, Gorayeb & Filho 2009[7]) (Mitchell et al. 2009[1]) (Keenan & Joseph 2010[4]) (Kinrade, Jackson & Tomnay 2010[1]) (Mitchell & Chaboyer 2010[1]) (Buckley & Andrews 2011[1]) (Proch 2011[3]) (Berney, Haines & Denehy 2012[1]) (Hardin 2012[3]) (Bishop, Walker & Spivak 2013[3]) (Rukstele & Gagnon 2013[3]) (Al-Mutair et al. 2013[1]) (Davidson et al. 2014[3]) (Kentish-Barnes et al. 2015[5,2]).

Section	Critical analysis review summary	References
2.5 Implications of PFCC for the ICU patient	The references were sourced from English language, grey papers and peer reviewed journals, from Australia[1], UK[2], USA[3], Canada[4] and Europe[5]. The time period was from 1979-2015. The ICU patient often lacks capacity due to the severity of their illness and is often the passive participant in PFCC. PFCC has been studied extensively in the paediatric and geriatric setting but not as widely in the ICU setting. Therefore, these articles provided a combination of general PFCC and explored the ICU setting, which was limited. In particular the references were scrutinised for benefits and improved outcomes for the patient. This led to the work of Donabedian (1988), the Picker Institute (2008) and McCormack and McCance (2006) that assisted develop the theoretical framework.	(Molter 1979[3]) (Donabedian 1988[3]) (Roland et al. 2001[3]) (Azoulay et al. 2003[5]) (Damboise & Cardin 2003[3]) (McCormack & McCance 2006[2]) (McAdam, Arai & Puntillo 2008[3]) (Morris et al. 2008[3]) (Picker Institute 2008[3]) (Davidson 2009[3]) (Mitchell et al. 2009[1]) (Garrouste-Orgeas et al. 2010[5]) (Meterko et al. 2010[3]) (Nelson et al. 2010[3]) (Proch 2011[3]) (Wendler & Rid 2011[3]) (Hardin 2012[3]) (Kress & Herridge 2012[3]) (Al-Mutair et al. 2013[1]) (Bishop, Walker & Spivak 2013[3]) (Rukstele & Gagnon 2013[3]) (Cappellini et al. 2014[5]) (Fan et al. 2014[3]) (Kress & Hall 2014[3]) (Rathert, Wyrwich & Boren 2012[3]) (Luxford & Newell 2015[1])

2.6 Implications of PFCC for ICU Nurses	The references were sourced from English language, grey papers and peer reviewed journals, from Australia[1], UK[2], USA[3], Canada[4] and Europe[5]. The time period was from 1979-2015. Nurses are integral to PFCC however the implications and impact of PFCC on them was limited in the literature in 2015 when the study commenced. The seminal work by McCormack, B & McCance, T 2006, 'Development of a framework for person-centred nursing' formed part of the innovative theoretical framework and was chosen both for suitability and the reputation of the authors. Brendan McCormack is internationally recognised for his work in person-centred care development and research collaborating in Ireland, UK, Norway, The Netherlands, Canada, Australia and South Africa.	(McCormack & McCance 2006[2]) (Lee et al. 2007[3]) (Charmel & Frampton 2008[3]) (Flinkman, Leino-Kilpi & Salanterä 2010[5]) (Black, Boore & Parahoo 2011[2]) (Cannon 2011[3]) (Ciufo, Hader & Holly 2011[3]) (Adams et al. 2014[3]) (Cappellini et al. 2014[5]) (Roche et al. 2014[1]) (Duffield et al. 2014[1]) (Luxford & Newell 2015[1])
2.6.1 Workplace stress for ICU Nurses	The references were sourced from English language, grey papers and peer reviewed journals, from Australia[1], UK[2], USA[3], Canada[4], Europe[5] and South Africa[6] the time period was from 1981-2015. These references were a combination of seminal work from Gray-Toft and Anderson (1981 and 1985) in relation to nursing stress, and other research that had looked at nursing stress in the ICU setting which was limited. The majority of the references coming from the USA.	(Gray-Toft & Anderson 1981a[3]) (Gray-Toft & Anderson 1981b[3]) (Gray-Toft & Anderson 1985[3]) (McCormack & McCance 2006[2]) (Embriaco et al. 2007[5]) (Davidson et al. 2007[3]) (Mitchell et al. 2009[1]) (Azoulay et al. 2009[5]) (Griffiths 2009[2]) (Gurses & Carayon 2009[3]) (Gurses, Carayon & Wall 2009[3]) (Stayt 2009[2]) (McCarthy, Power & Greiner 2010[2]; Shorter & Stayt 2010[2]) (Buckley & Andrews 2011[1]) (Hoonakker et al. 2011[3]) (Nixon et al. 2011[3]) (AIHW 2012[1]; Curtis et al. 2012[3]) (Obringer, Hilgenberg & Booker 2012[3])

		(Kompanje, Piers & Benoit 2013[5]) (Teixeira et al. 2013[5]) (Adams et al. 2014[3]) (Curtis, Sprung & Azoulay 2014[3]) (Naidoo & Sibiya 2014[6]) (Trankle 2014[1]) (Schubart et al. 2015[3])
2.7 Implications of PFCC for the healthcare system	The references were sourced from English language, grey papers and peer reviewed journals, from Australia[1], UK[2], USA[3], Canada[4] and Europe[5], the time period was from 2003-2015. The focus of this element of the literature review was to find evidence that PFCC could improve outcomes for the healthcare system. To this effect there was limited research when the study was being set up in relation to the outcomes on the healthcare system of PFCC. This has been identified as an area for ongoing research.	(Rapoport et al. 2003[3]) (Rechner & Lipman 2005[1]) (Gruenberg et al. 2006[3]) (Negrini et al. 2006[2,3,4,5]) (Charmel & Frampton 2008[3]) (Morris et al. 2008[3]) (O'Connor & Walsham 2009[2]) (Shelton et al. 2010[3]) (Unroe et al. 2010[3]) (Vasilevskis et al. 2010[3]) (Berney, Haines & Denehy 2012[1]) (Pastores, Dakwar & Halpern 2012[3]) (Tan et al. 2012[5]) (Winkelman et al. 2012[3]) (Duffield et al. 2014[1]) (McLaws & Jarvis 2014[1]) (Roche et al. 2014[1]) (The Health Foundation 2014a[2]) (Luxford & Newell 2015[1])
2.8 Theoretical framework	The references were sourced from English language, grey papers and peer reviewed journals, from Australia[1], UK[2], USA[3], Canada[4] and Europe[5], the time period was from 1979-2015. As there is no consistent framework for PFCC, this unique framework was developed after reviewing the literature in tandem with the aims of the organisational needs at the study site. The application of the SPO model developed by Donabedian (1988), Picker's Principles (2008) and McCormack and McCance's (2006) Person Centred Nursing	(Molter 1979[3]) (Donabedian 1988[3]) (McCormack & McCance 2006[2]) (Maxwell, Stuenkel & Saylor 2007[3]) (Picker Institute 2008[3]) (Bailey et al. 2009[4]) (Mitchell et al. 2009[1]) (McCarthy, Power & Greiner 2010[2]) (Nelson et al. 2010[3]) (Cannon 2011[3]) (Stricker et al. 2011[5]) (IPFCC 2012[3]) (Kitson et al. 2013[1]) (Rukstele & Gagnon 2013[3]) (Schleyer & Curtis 2013[3]) (Curtis, Sprung & Azoulay 2014[3]) (Rathert, Wyrwich & Boren 2012[3])

	framework were chosen for the authority in the subject matter and that they aligned with the philosophy of the study. Other research that had used these models were then examined to support the suggested framework.	

2.3 Defining patient and family centred care

As the literature search commenced it became clear that multiple terms for PFCC were often used interchangeably (McCormack et al. 2010). A review of 60 papers from medical and nursing health policy to identify the core elements of patient-centred care, found different definitions used (Kitson et al. 2013; Molter 1979). The lack of an agreed upon, or broadly consistent definition for PFCC, is partially due to the multiple terms used for it (Kitson et al. 2013; The Health Foundation 2014a). The consequence of the lack of clear definition is that implementation and integration of PFCC is challenging (The Health Partnership 2015). The various theoretical frameworks developed for different environments can make implementation of PFCC have a narrow focus, and may give rise to, a lack of integration in this effort (McCormack et al. 2010).

Globally, PFCC research has been driven by a body of inquiry from organisations involved in quality healthcare standard setting. Such organisations as: in the UK - The Health Foundation, The King's Fund and The National Health Service (NHS); in the USA - The Institute of Healthcare Improvement (IHI), The Institute of Medicine (IOM), The Institute for Patient and Family Centred Care (IPFCC) and The Picker Institute; in Australia - Federal and State governments, the Australian Commission on Safety and Quality in Health Care (ACSQHC) and NSW, Clinical Excellence Commission (CEC).

Much has been written both nationally and internationally about PFCC as it has become a main policy driver for quality and safety healthcare reform (Kitson et al. 2013). A review by The Health Foundation stated that over 200,000 articles had been published about aspects of person-centred care (The Health Foundation 2014a).

In 2014-15 The Health Foundation, UK, conducted an international review, to better understand why, even though person-centred care is embedded in government policy in the English speaking world, its application was episodic and fragmented (The Health Partnership 2015). The issues that this review identified were: person-centred care had developed differently in different health disciplines and jurisdictions; and, there is lack of a commonly used definition of person-centred care (The Health Partnership, 2015).

In Australia, the National Safety and Quality Health Service (NSQHS) Standards were developed by the ACSQHC and endorsed by the State Health Minsters in 2011 (ACSQHC 2012). These standards offer a national approach to safety and quality systems for healthcare in Australia. Standard 2 is titled, *Partnering with Consumers.* The intention of this standard is to encourage partnerships between the health professionals and the patient and families to enhance patient safety and underpins all of the other standards(ACSQHC 2012).

The NSW CEC, *Partnering with Patients Program* supports LHDs across NSW to actively engage patients, family and carers as health team members with the aim of improving safety and quality in healthcare (CEC 2015). Having these uniform national standards has enabled hospitals to have clearer guidance and definition of PFCC in the Australian context.

Different definitions and dimensions of PFCC terms are presented in Table 2.4. This selection of literature demonstrates that even though there is no consistent definition used, nevertheless there are overarching principles and benefits of PFCC and recurring words are *partnership* and *respect.* The principles of PFCC include, that it is a philosophical approach to care that recognises the needs of patients and their family members and the important role that family members play during a patient's illness (Henneman & Cardin 2002; Needham et al. 2012). This is a paradigm shift from a disease centred approach (Rukstele & Gagnon 2013) and a clearly articulated move towards a partnership approach to healthcare that involves patients, families and the healthcare providers (ACSQHC 2010) rather than the patient alone (Mitchell et al. 2009).

Table 2. 4: Definitions and dimensions of PFCC from key agencies

Country	Agency	Definition	Dimensions
Australia	Australian Commission on Safety and Quality in Health Care Patient Centred Care: Improving Quality and Safety by Focusing on Patients and Consumers (ACSQHC 2010) National Safety and Quality Health Service Standards(ACSQHC 2012)	**Partnership** approach to healthcare between patients' families and healthcare providers **Respectful** of and responsive to individual patient preferences, needs and values.	• **Respect** • Emotional support • Physical comfort • Information and communication • Continuity and transition of care coordination • Involvement of family and care**rs** • Access to care
	Clinical Excellence Commission (CEC) NSW www.cec.health.nsw.gov.au (CEC 2015)	**Respectful** of and responsive to individual patient preferences, needs and values.	

Country	Agency	Definition	Dimensions
United Kingdom	The Health Foundation Helping Measure Patient Centred Care (The Health Foundation 2014a)	A philosophy that sees patients as equal **partners** in planning, developing and assessing care	• Patient participation and involvement • **Relationship between the patient and healthcare professional** • Context where care is delivered
	The Health Partnership The state of play in person-centred care: A pragmatic review of how person-centred care is defined, applied and measured (The Health Partnership 2015)		• Affording people dignity, **respect** and compassion • Offering coordinated care, support and treatment Offering personalised care support and treatment enabling
United States	The Institute for Healthcare Improvement www.ihi.org (IHI 2015)	Putting the patient and the family at the heart of every decision and empowering them to be genuine **partners** in their care	• Developing care pathways that are co-designed and co-produced with individuals and families • Ensuring that people's care preferences are understood and honoured, including at the end of life • **Collaborating with partners** on programs designed to improve engagement, shared decision making, and compassionate, empathetic care • Working with partners to ensure that communities are supported to stay healthy and to provide care to their loved ones closer to home.
	The Institute of Medicine Crossing the Quality Chasm (Institute of Medicine (IOM) 2001)	Providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions	• **Respectful** to patients' values, preferences and expressed needs • Coordinated and integrated • Provide information, communication and education • Ensure physical comfort • **Provide emotional support, relieving fear and anxiety** • Involve family and friends
	Institute for Patient and Family Centred Care www.ipfcc.org (Johnson,	**Partnership** with families and carers in the planning, delivery and evaluation of	• **Dignity and respect** • Information sharing • Participation

Country	Agency	Definition	Dimensions
	Abraham & Shelton 2009)	healthcare that is grounded in mutually beneficial partnerships among patients, families and healthcare providers.	• Collaboration
	Picker Institute (Picker Institute 2008)	Patient-centred care is the practice of caring for patients (and their families) in ways that are meaningful and valuable to the individual patient.	• **Respect** for patients' values, preferences and expressed needs • Coordination and integration of care • Information and education • Physical comfort • **Emotional support and alleviation of fear and anxiety** • Involvement of family and friends • Continuity and transition • Access to care

For the purpose of this study the definition of PFCC that will be used is *partnership approach to healthcare between patients families and healthcare providers* (ACSQHC 2010). This definition aligns closely with the study focus, that is, PFCC is an important approach to delivering healthcare as it is about working with the family and patient, rather than doing to and for them (ACSQHC 2012; Johnson, Abraham & Shelton 2009; Picker Institute 2008). This study adopted a PFCC approach because it has been widely endorsed as an optimal framework to improve the quality of healthcare leading to better health outcomes (Charmel & Frampton 2008; Donabedian 1988; Maxwell, Stuenkel & Saylor 2007; McCormack & McCance 2006; Picker Institute 2008). Additionally, the PFCC approach can assist organisations meet key performance indicators (KPIs), such as length of stay and improve patient and family experience of care (Luxford & Newell 2015; Maxwell, Stuenkel & Saylor 2007). It also provides nurses with a clear meaning and purpose as there is the human to human connection which has been reported to improve staff satisfaction (Luxford & Newell 2015; Watson & Frampton 2008).

Conversely it has been argued that due to the many variables in the healthcare setting, research has not measured the effects of family presence on patient safety and it is difficult to attribute and understand how specific PFCC processes relate to outcomes (Davidson 2009; Rathert et al. 2015). This was an identified gap in the knowledge. The aim of this study is to

assess effects of family presence, with family assisted passive exercising of unconscious relatives in the ICU on the families, nurses, patients and the healthcare system.

2.4 Implications of PFCC for the family of patients in ICU

Families of ICU patients have unique psychological challenges as normally they have little time to adjust to their family member's admission to hospital (Coyer 2004; Eggenberger & Nelms 2007; Kinrade, Jackson & Tomnay 2010). By providing families with opportunities to participate in the passive exercises of their relative it was anticipated that, as with previous PFCC studies and in keeping with Picker's principles of PFCC, emotional, and additionally, informational needs of the family would be better met and anxiety reduced (Azoulay et al. 2003; Davidson 2009; Lam & Beaulieu 2004; Maxwell, Stuenkel & Saylor 2007; Molter 1979; Picker Institute 2008; Wong et al. 2015). This would occur as there would be opportunities for the family to give and receive information about the patient (Eggenberger & Nelms 2007; Picker Institute 2008), thus improving their confidence in the care their relative was receiving (Cannon 2011; Kinrade, Jackson & Tomnay 2010; Maxwell, Stuenkel & Saylor 2007).

It has been reported that families wish to stay at the bedside of their family member when they are in an ICU (Cappellini et al. 2014). Participation in care is reported as beneficial to families as they learn to cope with their relatives' ICU admission (Garrouste-Orgeas et al. 2010; Maxwell, Stuenkel & Saylor 2007; Picker Institute 2008). By involving families it recognises them as partners-in-care, rather than visitors and, consequentially, acknowledging the importance of the family unit (ACSQHC 2010; Coyer 2004; Johnson, Abraham & Shelton 2009; Picker Institute 2008). In a busy ICU, with the focus on the patient, particularly in the first few hours and days, the family can be overlooked and their needs not met (Nolen & Warren 2014). It is important that family needs are met and that they are satisfied with patient care (Cannon 2011) as they are the proxy for patient satisfaction and play an essential role in daily decision making for the patient (Bailey et al. 2009; Cannon 2011; Curtis, Sprung & Azoulay 2014; Mitchell et al. 2009; Nolen & Warren 2014; Rukstele & Gagnon 2013; Schleyer & Curtis 2013; Stricker et al. 2011).

2.4.1 Family needs in ICU

The needs of family members of ICU patients have been studied extensively since Molter's (1979) seminal examination of family members' needs, led to the development of the CCFNI instrument (Bailey et al. 2009; Leske 1991; Molter 1979; Nolen & Warren 2014). The CCFNI has been used in a variety of clinical settings around the world to measure family needs (Azoulay et al. 2003; Bailey et al. 2009; Baning 2012; Burr 1998; Gentry et al. 2014; Kinrade, Jackson & Tomnay 2010; Leske 1991; Maxwell, Stuenkel & Saylor 2007; Nolen & Warren 2014; Obringer, Hilgenberg & Booker 2012); along with the NMI that was developed by Warren (1994) to assess whether those needs identified on the CCFNI were met (Bailey et al. 2009; Nolen & Warren 2014; Warren 1994). However, the CCFNI instrument has had limited use, measuring the impact of a family intervention (Baning 2012).

Family needs are categorised with the CCFNI tool into five domains that are: information, proximity to the patient, assurance, support and comfort (Bailey et al. 2009; Maxwell, Stuenkel & Saylor 2007; Molter 1979; Nolen & Warren 2014). Studies that have used the CCFNI as a measure of family satisfaction consistently identify the domains of assurance, information and proximity (which are patient related needs), as the most important needs as identified by the family (Al-Mutair et al. 2013; Bailey et al. 2009; Baning 2012; Burr 1998; Gentry et al. 2014; Kinrade, Jackson & Tomnay 2010; Lam & Beaulieu 2004; Maxwell, Stuenkel & Saylor 2007; Molter 1979; O'Neill-Norris & Grove 1986; Obringer, Hilgenberg & Booker 2012). Conversely, research has ranked low priority to the domains of support and comfort, which are the more personal needs of the family member (Burr 1998; Maxwell, Stuenkel & Saylor 2007).

To expand on the domains of the CCFNI, a paramount need for the family in helping them deal with their loved ones hospitalisation is receiving consistent information (Kitson et al. 2013; Nolen & Warren 2014; Sheaffer 2010; Wong et al. 2015). This can be achieved by communication with key staff taking care of their relative at the bedside, who can explain what is happening to the patient. This not only reassures the family member but can help them retain a sense of control (Al-Mutair et al. 2013). In spite of this knowledge, poor or fractured communication is still identified as an issue in the ICU setting (Davidson, Jones & Bienvenu 2012). This arises particularly if the subject to be discussed with the family is around death and dying (Ciufo, Hader & Holly 2011; Trankle 2014).

It has been identified, by surveying bereaved relatives from ICU, that there is a relationship between proximity to the patient and satisfaction with care and dissatisfaction when there is restricted access (Lee et al. 2007; Trankle 2014). Unrestricted visiting has been identified in the top ten needs of families of patients in the ICU (Lee et al. 2007; Riley et al. 2014). Proximity to the patient helps family members maintain relationships and remain emotionally close, as they are providing support to their relative (Cappellini et al. 2014; Ciufo, Hader & Holly 2011; Maxwell, Stuenkel & Saylor 2007) and ensures an holistic approach to PFCC (Nolen & Warren 2014). However there are still restrictions in place in many ICUs. Some would argue more for the benefit of the staff, who perceive families as getting in the way of workflows, than the family and patients (Ciufo, Hader & Holly 2011; Kean & Mitchell 2014; Lee et al. 2007). Whereas some other families would agree with the clinical staff taking care of their relative, that the focus needs to be on the patient rather than them and rank this need lower (Burr 1998). When this study commenced in the ICUs, there were still restrictions around visiting times. It was anticipated that from this study, the nurses would observe the benefits of the families being present when assisting with the passive exercises; and this in turn would support more flexibility in visiting times.

The anticipated effect of PFCC on the families of ICU patients is that stress levels will be reduced as their needs will be met (Baning 2012; Sheaffer 2010). This is important as critical illness of a family member is known to negatively impact the entire family (Bailey et al. 2009; Kentish-Barnes et al. 2015; Kinrade, Jackson & Tomnay 2010; Leske 1998; Maxwell, Stuenkel & Saylor 2007). This is particularly the case with ICU admission, which is often unplanned and the ongoing effects for both the family and patient can take years to resolve (Herridge 2011) if ever, and death is a real probability (Callahan & Supinski 2013).

Even if the family member does not die, families may experience lifestyle challenges as established family roles are disrupted (Coyer 2004; Molter 1979). There may be: loss of earning; becoming a carer to a family member; or they may experience other stressors associated with the hospitalisation, such as anxiety and depression (Callahan & Supinski 2013; Kentish-Barnes et al. 2015; Maxwell, Stuenkel & Saylor 2007; Morris et al. 2008).

2.4.2 Families assisting with care in ICU

Previous studies have shown that families may want to be involved in care (Al-Mutair et al. 2013; Henneman & Cardin 2002; McAdam, Arai & Puntillo 2008; Mitchell et al. 2009; Mitchell & Chaboyer 2010; Proch 2011), as a way of demonstrating that they care (Mitchell et al. 2009). That the inclusion of the family in assisting with care can provide them with some satisfaction and reassurance (Al-Mutair et al. 2013) as this makes them feel more involved and helpful. Participation, particularly if they see their family member improving (Keenan & Joseph 2010), or can see that what they are doing is providing some physical comfort (Picker Institute 2008), can be emotionally reassuring in a challenging environment.

It has been reported that for relatives not included in care delivery, there may be feelings of powerlessness, fear, disorientation, and development of adversarial relationships between families and care givers (Buckley & Andrews 2011; Casarini, Gorayeb & Filho 2009; Davidson, Jones & Bienvenu 2012). Helping with care can, also address a fundamental need of many family members, which is to safeguard the patient (Burr 1998; Davidson et al. 2014). Conversely, it has been reported that the family members have not necessarily seen participating in care as the most important aspect of need or satisfaction in ICU (Kinrade, Jackson & Tomnay 2010).

Australian research explored families' experiences of providing physical care with the support of critical care nurses (Mitchell et al. 2009). Although there were limitations to this study with a small sample size of ten and all participants had to be English speaking, it identified that there were, nevertheless, benefits of involving family with care. Those benefits included improved communication between the family and the nurses and the physical and emotional contact between the family and the patient that occurred in the process of providing care. Family members also reported that they felt useful and less helpless when assisting with care, and that it empowered them by giving them something to do (Mitchell et al. 2009).

A study in the USA, which involved family in early progressive mobility of their relative in the ICU, demonstrated that family members were willing to participate in patient care (Rukstele & Gagnon 2013). The benefit identified from this study was the connection that the family had with both the patient and the nurses, which allowed sharing of information and the

family knowing what was happening with their relative. It was also an opportunity to educate the family.

Additionally, there may be disadvantages, such as family fatigue and stress from long hours at the bedside and family guilt if the patient does not do well in spite of their best efforts (Kentish-Barnes et al. 2015; McAdam, Arai & Puntillo 2008). Some family members may be older and be uncertain that they can help or, indeed, that they may not have the capacity to assist (Hardin 2012).

In summary there was a perceived gap in the knowledge about the participation of families in the ICU. Studies have not examined, families assisting with passive exercises, and, as previously highlighted, it has not been demonstrated that passive exercises are beneficial (Berney, Haines & Denehy 2012). This was identified as an important need to add to the knowledge that warranted further investigation.

As there have been different findings in relation to the benefits of families assisting with care, it was decided to further explore the benefits of family members contributing to care. In particular, focusing upon passive exercises and building on the previous research by Mitchell and colleagues (Mitchell et al. 2009) and to test the conclusions of Azoulay et al. *most ICU caregivers are willing to invite family members to participate in patient care, but most family members would decline* (Azoulay et al. 2003).

On the basis of the above review, Picker's domains of PFCC (Picker Institute 2008) is a useful framework for investigating family perspective of family assisted passive exercise in ICU. These principles have been adopted in Australia by the ACSQHC and will be discussed further at the end of this chapter in section 2.10.

2.5 Implications of PFCC for patients in ICU

This section focuses upon the implications of PFCC for patients in ICU.Patients admitted to the ICU commonly lack decision making capacity. The extent of this has been estimated to be as high as 95% of all patients (Wendler & Rid 2011). They are vulnerable, as they are unable to talk to the doctors and nurses looking after them and provide a medical history. In keeping with PFCC principles having a family member close by is multifactorial (McAdam, Arai &

Puntillo 2008; Picker Institute 2008). PFCC not only provides emotional support to the family, but can reassure the patient knowing that their family is close by (Mitchell & Chaboyer 2010). The family can be: an active presence watching over the patient; be a surrogate decision maker and an advocate for the patient when they cannot advocate for themselves (Hardin 2012); they can be the historian providing the medical history, which will assist the medical and nursing staff provide optimal and safe care, for example reducing medication errors such as drug allergies (Hardin 2012); they can be a voluntary caregiver and assist with treatments that are beneficial to the patient and provide physical comfort (Hardin 2012; Picker Institute 2008).

Another reported benefit of PFCC for the conscious patient who is aware of their surroundings is, that it can reassure them and make them feel secure (Al-Mutair et al. 2013; Bishop, Walker & Spivak 2013; Cappellini et al. 2014; Garrouste-Orgeas et al. 2010; Hardin 2012; McAdam, Arai & Puntillo 2008; Molter 1979; Nelson et al. 2010; Roland et al. 2001). However the literature in relation to the outcomes for unconscious patients of PFCC informed approaches in the ICU setting was limited as the benefits tended to be more family focused (Bailey et al. 2009; Maxwell, Stuenkel & Saylor 2007; Molter 1979) . This was an identified gap in the knowledge that this study sought to address.

It has also been reported that a PFCC approach may improve clinical outcomes for the patient and enhance their recovery process (Azoulay et al. 2003; Damboise & Cardin 2003; Davidson 2009; Luxford & Newell 2015; McAdam, Arai & Puntillo 2008; Rukstele & Gagnon 2013). Some examples in the literature are, that PFCC may: decrease confusion (Rukstele & Gagnon 2013); reduce the incidence of ventilator associated pneumonia by families assisting with mouth care (Proch 2011); reduce ventilator hours and length of stay with early mobilisation of patients (Damboise & Cardin 2003; Kress & Hall 2014; Morris et al. 2008; Rukstele & Gagnon 2013) as well as reduce mortality (Meterko et al. 2010).

As discussed in Chapter 1, one known frequently observed complication of survival of critical illness for a patient is muscle wasting and weakness, which has been estimated to occur in approximately 25% of ICU patients (Fan et al. 2014). The implications of this is that many patients who require an ICU admission will require significant rehabilitation if they survive their initial illness (Kress & Herridge 2012). Given the magnitude of the debilitation that can occur following an ICU admission and to improve the understanding of the impact of

PFCC in the ICU setting and how it relates to patient outcomes, further research is warranted (Davidson 2009; Rathert, Wyrwich & Boren 2012). In this study it was to determine if an intervention such as passive exercising with family assisting, could slow down or halt the process of muscle wasting. This had not been previously demonstrated and was an identified gap in the knowledge base.

The concept of an overarching quality model, led the research to Donabedian's structure, process and outcome (SPO) model (Donabedian 1988). This model provides a framework for this study to investigate the process of family assisted passive exercise in ICU for quality outcomes. This model has been used extensively to support quality improvement and will be discussed further at the end of this chapter in section 2.10.

2.6 Implications of PFCC for ICU nurses

Nurses are in a position to provide support to family members and therefore facilitate PFCC (Adams et al. 2014). It has been reported that PFCC can increase patient and family satisfaction and this in turn can increase employee satisfaction (Charmel & Frampton 2008; Luxford & Newell 2015). It has also been reported that if staff needs are better met, not only can their satisfaction levels be improved but this could improve the quality of patient care and family support (Flinkman, Leino-Kilpi & Salanterä 2010). Conversely, it has also been reported that implementing and maintaining a PFCC approach can be challenging and stressful for nurses as they relinquish control (Lee et al. 2007). That although nurses recognise that there are benefits for the patient and family of PFCC, for example open visitation reducing patient and family anxiety, that, it may be at the expense of nursing staff satisfaction (Cappellini et al. 2014; Kean & Mitchell 2014; Lee et al. 2007). A challenge in the ICU setting is how to constructively engage families to assist with the care provided. It has been reported that nurses may perceive families assisting with care, as a further complication in the delivery of patient care, contributing to an already stressful environment (Cannon 2011; Ciufo, Hader & Holly 2011; Kean & Mitchell 2014).

2.6.1 Workplace stressors for ICU nurses

The ICU is a specialised area requiring highly skilled nurses to look after complex critically unwell patients and their families. However, it can take time for nurses to develop and feel

confident in their skills and knowledge in this demanding context. It can be argued that more inexperienced nurses may feel inadequately prepared to deal with such complex issues and the emotional needs of ICU patients and their families, who require more attention, compassion and sympathy when faced with the immediate prospect of dying (Naidoo & Sibiya 2014).

Previous studies found that nurses engaged in direct care of the patient can experience a greater level of stress than, for example, a nursing manager (McCarthy, Power & Greiner 2010). The cause of stress in this environment is multifactorial, for example: the use of advanced life-sustaining measures in patients with poor long term prognosis can lead to futile, disproportionate or inappropriate care with suboptimal outcomes which can be ethically challenging for the nurse (Kompanje, Piers & Benoit 2013; Teixeira et al. 2013). Further there may be conflict around decisions of care and treatment if there is lack of understanding and agreement between family and care givers as to how far to go with treatment (Adams et al. 2014). The patients may require interventions that are painful and confronting for the families and nurses looking after them(Shorter & Stayt 2010). Nurses looking after patients for a prolonged period in the ICU develop relationships with them and their families in emotionally intense contexts and there may be discussions with the family about the patient's treatment and approaching death (Naidoo & Sibiya 2014; Shorter & Stayt 2010). The subsequent emotional toll of seeing someone that you have cared for suffering, fail to improve then subsequently die can and does cause distress (Gray-Toft & Anderson 1981a; Gray-Toft & Anderson 1981b, 1985; Kompanje, Piers & Benoit 2013; McCarthy, Power & Greiner 2010).

Communication and miscommunication has been identified as a major stressor for both the family and care giver (Curtis et al. 2012; Curtis, Sprung & Azoulay 2014; Davidson et al. 2007; Mitchell et al. 2009). As discussed in Section 2.4.1, the family of ICU patients are often required to communicate with care providers to assist with decision making when those family members are at their most vulnerable (Adams et al. 2014). The number of individuals involved in the patient's care in ICU can also increase the complexity of the decision process, as does the need for quick decisions on the part of the family member (Schubart et al. 2015). Families have identified that receiving inconsistent information is stressful for them (Obringer, Hilgenberg & Booker 2012). This inconsistency in communication can lead to

stressful interactions with the nurses who may be ill equipped to deal with such interactions (Azoulay et al. 2009; Trankle 2014).

In a highly charged environment such as an ICU, the tone and choice of words, verbal and non-verbal cues can greatly impact on the interactions between the staff and family, both positively and negatively. Family members are understandably emotional in the ICU, but the potential for emotion to create communication problems is not limited to family members but can also be from the nurses looking after the patient (Stayt 2009). Workplace stress for nurses increases when they do not have adequate information to answer the questions of families. It has been reported that PFCC may help reduce any adversarial relationships between family and caregivers (Buckley & Andrews 2011).

Nursing workload is a common term used in the health literature, but often without clear definition. Understanding the variables implicit in workload is difficult due to local nuances of staffing ratios and perceptions by staff. Some universally accepted issues that impact on workload are: inadequate supply of nurses that can impact on the skill mix; the reduction in length of stay for patients that impacts on hospitals only having the sickest people (Gurses & Carayon 2009); shift patterns, such as night duty and length of shift (Embriaco et al. 2007).

As health continues to consume larger amounts of gross domestic product, estimated in Australia at 10.3% in 2015-2016 financial year (AIHW 2012). Budgetary constraints impact on available resources and staffing levels, which in turn impacts on the ratio of patients to clinicians. This can have negative consequences for the patient, as their care can be compromised due to lack of nursing hours to look after their needs (Griffiths 2009; Gurses, Carayon & Wall 2009).

All of these factors in the ICU can cause stress for the nurses. This is important to understand, as excessive workload has been reported to negatively affect the physical and emotional health of employees. Stress can lead to long term diseases (Nixon et al. 2011) and be the cause of employee burnout (Hoonakker et al. 2011). This in turn leads to staff that are unable to meet the needs of their patients and families, which ultimately impacts on PFCC.

Stress in nursing has been widely studied, but it still warrants further investigation as the different variables of local contexts, care models and management resources may impact on the outcome (McCarthy, Power & Greiner 2010). The literature is limited in relation to the

impact that a PFCC approach has on nurses and their stress levels. There is a gap in the knowledge in relation to the impact that family assisting with passive exercising of their relative in ICU would have on nurses' stress and satisfaction. This was seen as a critical deficit and warranted further investigation.

The above review of dynamics between PFCC and ICU nurses led the research to the person-centred nursing framework developed by McCormack and McCance (McCormack & McCance 2006). This framework, which was informed by Donabedian's SPO model, confirms the rationale of investigating nurses' perspective of applying family assisted exercise in ICU in this study. This literature will be discussed at the end of this chapter in section 2.10.

2.7 Implications of PFCC for the healthcare system

It has been established that the cost of keeping a patient in the ICU is more expensive than care that is provided in a ward. The estimated cost, from different studies internationally, is that ICU beds take up approximately 20% of a hospital budget (Berney, Haines & Denehy 2012; Pastores, Dakwar & Halpern 2012). There are a number of variables that account for the overall cost incurred by an ICU including: case-mix of patients; occupancy rate of the unit; skill mix of the staff and variations in medical practice (Tan et al. 2012). In a quaternary referral hospital that has a more complex case-mix of patients many of these factors are outside the control of an individual unit.

The first day in ICU is reported to cost approximately four times as much, and other ICU days are approximately two and a half times as much, as non-ICU hospital days (Pastores, Dakwar & Halpern 2012; Rapoport et al. 2003; Unroe et al. 2010). Research across 329 ICUs in France, UK, Germany and Hungary (Negrini et al. 2006) and seven ICUs in Germany, Italy, UK and the Netherlands (Tan et al. 2012) to ascertain costing, confirmed that there was significant variance but that labour was the main cost driver in all cases. This is no different to the costs of caring for patients in an ICU of a tertiary referral hospital in Australia, where spending estimates for the financial year 1 July 2002 to 30 June 2003, showed that 69% were staff related (Rechner & Lipman 2005). Costing estimates assessed an ICU admission between $2670 to $6801 (McLaws & Jarvis 2014; Rechner & Lipman 2005). Similarly at the research site for the 2013-14 financial year 65% of the running costs were staff related. As

obtained from the budget reports, the average cost per patient admission was $2000 per day and an average cost per patient stay of $10,338.

When considering the implications of PFCC on the healthcare system the focus is whether there are any efficiencies that can be attributed to it, such as; the retention of nurses (Duffield et al. 2014; Roche et al. 2014); reduction in length of stay for the patient (Shelton et al. 2010); improved clinical outcomes or patient safety (Luxford & Newell 2015). PFCC has been identified as crucial and essential for providing quality care (The Health Foundation 2014a) and in the ICU setting that it may decrease resource utilisation (Charmel & Frampton 2008; O'Connor & Walsham 2009; Vasilevskis et al. 2010). If employees are more satisfied this could improve the retention and decrease absenteeism (Luxford & Newell 2015). Staff retention is important for the organisation due to the costs incurred on the budget for that replacement (Duffield et al. 2014). The estimated costs of replacing nurse turnover, in an Australian study in 2014, showed considerable variation across the 11 different facilities in the study. The average cost across those 11 hospitals being $49,255 per full time equivalent (FTE) (Roche et al. 2014).

Overall, it is difficult to precisely measure the total impact of PFCC on the healthcare system, both financial and non-financial. For example, reducing the ventilator hours and length of stay for one patient does not negate the need to use the bed and nurses for another patient. Length of stay in the ICU is a common outcome measure in randomised trials of ICU (Shelton et al. 2010), but as many patients die in ICU it is difficult to attribute an intervention on length of stay from the effects of mortality (Gruenberg et al. 2006). Previously research in relation to early physical therapy in ICU patients has demonstrated a possible reduction in, hospital and ICU length of stay and duration of mechanical ventilation by improving muscle strength as well as reducing mortality (Morris et al. 2008; O'Connor & Walsham 2009; Winkelman et al. 2012). However none of this research was with family-assisted therapy.

The literature did not appear conclusive in that PFCC in the ICU improved healthcare efficiencies and there was an identified gap in the literature in relation to how family assisting with passive exercises would impact on the healthcare system. This was to be examined using the unique theoretical framework developed for this study, which is presented in section 2.10.

2.8 Strengths and limitations of the literature search and review

The literature search and review strategy was driven by a number of factors, including: local needs to improve understanding, practice skills and knowledge; need to integrate with development activities underway in the ICU; and, policy developments initiated by the State government and the LHD. As a result, and as noted above, an emergent iterative approach was adopted which provided flexibility and capacity to engage, nurture and maintain staff participation in the study. This was the strength of the search approach and review. The downside of the approach adopted was there could have been more a structured and systematic approach to the task. There was not an evaluation of the quality of the research articles. Some of the studies had small sample sizes and therefore may not be transferable to other settings.

2.9 Research question and significance of the study

The above review of literature (sections 2.4 to 2.7) confirms there are still challenges in defining and sustaining PFCC for an ICU setting with unconscious patients. This study was an opportunity to examine the impact that involving family with passive exercising of their unconscious relative in ICU would have on the family, patient, nurses and healthcare system. Therefore, this research will add knowledge to both the practice field and empirical literature.

This study aims to explore the concept of PFCC and identify areas where the needs of family were not being met, to guide future practice development. By involving the families with the care of their relatives, it was also anticipated that there would be improved communication between families and nurses. This could translate into addressing some of the nurses' workplace stressors and reduce stress levels and improve the workplace satisfaction of the nurses. Additionally, it was anticipated that early engagement of the family assisting with passive exercising of their relative, would not only address the five domains of family need identified by the CCFNI, but may halt or slow down muscle wasting and thereby improve patient and healthcare outcomes.

This study was warranted to answer the overall research questions:

Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for the families?
Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for the nurses?
Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for the patients?
Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for the healthcare system?

2.10 Theoretical framework

This study has explored the potential to decrease complications consequent on an acute episode of critical illness, with the use of PFCC. This outcome would, thereby, reduce the enormous burden on patients, families, nurses and healthcare system. This was to be investigated by involving the family member with passive exercising of their unconscious relative while they were admitted in the ICU. The focus was to generate a better understanding of the relationships between a PFCC initiative in an ICU setting and the impact that this had on: the family of ICU patients; ICU nurses; clinical outcomes for the ICU patient; and, healthcare system efficiencies.

There is no widely accepted consistent theoretical framework for PFCC (Kitson et al. 2013). Hence, a purpose-designed framework was developed for this study that suited the local environment to assess improvement of PFCC outcomes. This model is unique, drawing on a combination of frameworks to explore the issues for the patient, family, nurses and healthcare system. The model integrates the SPO quality model (Chaboyer, McMurray & Wallis 2010; Donabedian 1988; Liu et al. 2011, McCormack & McCance 2006: Santana et al. 2017), combined with Picker's patient-centred care principles (ACSQHC 2010; Picker Institute 2008) and McCormack and McCance's person-centred nursing framework (McCance, McCormack & Dewing 2011; McCormack & McCance 2006; McCormack, McCance, Slater & McCormack 2009;). The strength of this model is, that all the frameworks that were used in this study are from eminent sources, and have been used in previous research. This provides some assurance of their veracity.

2.10.1 Structure, process and outcome model

Donabedian (1988) published the SPO healthcare quality model, explicitly linking the three elements of structure, process and outcome, to improve the organisation and delivery of care. Although each element should logically lead to the next, such that structure leads onto the intermediate step of process and concludes with outcomes, it is recognised that there needs to be a pre-existing connection between the elements for quality assessment to occur (Donabedian 1988). This model has become the foundation for approaches to quality care and assessment for numerous quality and research projects (Chaboyer, McMurray & Wallis 2010; McCormack & McCance 2006). Donabedian's explanation for each element of the model is presented in Table 2.5 (Donabedian 1988) and this is followed by the relationship of the framework to this study as shown in Figure 2.2.

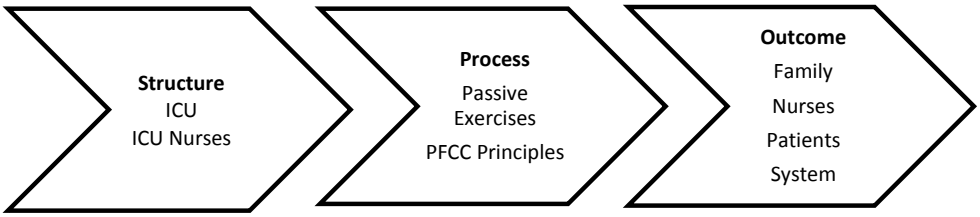
Table 2. 5: Elements of the Structure, process, outcome quality model

Element	**Explanation**
Structure	The structure relates to 'the attributes of the settings in which care occurs. This includes material resources of the setting in which care occurs, i.e. facilities, equipment and money. Also the human resources, such as the number, qualifications and the hierarchy of the staff, and the organisations classification, that is, a public or private hospital' (p.1745).
Process	The process of care is defined as 'what is done in the receiving and giving of care' (p.1745). This can cover a wide variety of interventions that can lead to measurable outcomes.
Outcome	'The effects of the care (process) on the population under study' (p.1745). Such as can be measured with survey instruments.

(Donabedian 1988)

The model was chosen as the basis for the study's theoretical framework as it has been previously reported that improvements in the structure of care should lead to improvements in clinical processes and, that should, in turn, lead to improved patient outcomes (Donabedian 1988; Rathert, Wyrwich & Boren 2012). It had also been used to guide the person-centred framework developed by McCormack and McCance, which this study would also draw on (McCormack & McCance 2006).

Figure 2. 2: SPO model as applied in the ICU context for this study



In this study the *structure* was categorised as the ICUs where the study took place, this included the active and control units. A full explanation of the setting can be found in Chapter 3. The structure also encompassed the ICU nurses, who not only formed the working party that provided the organisational support for the study; but were also responsible for either, supporting the families with the *process* of the passive exercises in the active unit, or doing the passive exercises in the control unit. Finally the *outcome* was the impact of the intervention of passive exercises on the families, nurses, patients and healthcare system. Each of these four elements was to be investigated using a combination of quantitative and qualitative instruments. The instruments are discussed fully in Chapter 3.

2.10.2 Picker Institute's eight principles of patient-centred care

The Picker Institute's eight principles of patient-centred care were developed as a collaboration between the Harvard Medical School, on behalf of the Picker Institute and The Commonwealth Fund (Picker Institute 2008). To do so they drew on the experiences of a variety of stakeholders, that included patients, families and healthcare workers. The principles, with an explanation of why these principles are important to patients and their families are shown in Table 2.6.

Table 2. 6: Picker Institute's eight principles of patient-centred care

Principle	Explanation
Respect for patient preference	Refers to involving and listening to patients and their families in decision-making. It is about recognising and honouring what may be unique perspectives and choices based on the diversity of cultural backgrounds.
Coordination and integration of care	Patients expressed feeling vulnerable and powerless in the face of illness. Patients identified three areas in which care coordination can reduce feelings of vulnerability: • Coordination of clinical care • Coordination of ancillary and support services • Coordination of front-line patient care
Information and education	Patients expressed their worries that they were not being completely informed about their condition or prognosis. To counter this fear, hospitals can focus on three kinds of

Principle	Explanation
	communication: • Information on clinical status, progress and prognosis • Information on processes of care • Information to facilitate autonomy, self-care and health promotion
Physical comfort	The level of physical comfort patients report has a significant impact on their experience. Three areas were reported as particularly important to patients: • Pain management • Assistance with activities and daily living needs • Hospital surroundings and environment
Emotional support	Fear and anxiety associated with illness can be as debilitating as the physical effects. Caregivers should pay particular attention to: • Anxiety over physical status, treatment and prognosis • Anxiety over the impact of the illness on themselves and family • Anxiety over the financial impact of illness
Involvement of family and friends	This principle addresses the role of family and friends in the patient experience. Family dimensions of patient-centered care were identified as follows: • Providing accommodations for family and friends • Involving family and close friends in decision making • Supporting family members as caregivers • Recognizing the needs of family and friends
Continuity and Transition	Patients expressed concern about their ability to care for themselves after discharge. Meeting patient needs in this area requires the following: • Understandable, detailed discharge information i.e. in regards to medications, physical limitations, dietary needs • Coordinate and plan ongoing treatment and services after discharge • Provide information regarding access to clinical, social, physical and financial support on a continuing basis
Access to care	Patients need to know they can access care when it is needed. Focusing mainly on ambulatory care, the following areas were of importance to the patient: • Access to the location of hospitals, clinics and physician offices • Availability of transportation • Ease of scheduling appointments • Availability of appointments when needed • Accessibility to specialists or specialty services when a referral is made • Clear instructions provided on when and how to get referrals

(Picker Institute 2008) https://www.picker.org/about-us/picker-principles-of-person-centred-care/

Although all the principles carry equal weight, in this study six of the principles were more prominent for the family and in the ICU setting and included: respect for patient preference; coordination and integration of care; information and education; physical comfort; emotional support; and, involvement of family and friends. The reasons for this are explained below.

As the patient is unconscious in the ICU the principles related predominately to the family members. It was anticipated that the family would be the proxy decision maker, as they would be likely to know what the patient's preferences were (Bailey et al. 2009; Cannon 2011; Curtis, Sprung & Azoulay 2014; Mitchell et al. 2009; Rukstele & Gagnon 2013; Schleyer & Curtis 2013; Stricker et al. 2011). By involving and educating families with the passive exercises of the patient, communication, and therefore the dissemination of

information, would be improved with the direct care nurses (Maxwell, Stuenkel & Saylor 2007; Nelson et al. 2010). The exercises would also address the physical comfort principle. Families and the patients require emotional support to allay their fears. This is particularly relevant in an ICU setting and has been achieved in other PFCC studies (Bailey et al. 2009; Maxwell, Stuenkel & Saylor 2007; Molter 1979).

The premise of PFCC requires the involvement of family and friends. This can be in decision making, supporting family members as caregivers and recognising the needs of family and friends (Davidson, Jones & Bienvenu 2012; Kitson et al. 2013; Mitchell et al. 2009; Molter 1979; Picker Institute 2008). In the study the nurses were to support the family to provide the passive exercises. It was perceived that this would also have the benefit of providing emotional support to the family (Nelson et al. 2010). The evaluation of the study was therefore based on the needs and satisfaction of family and looking at whether nurses and family perceptions of need aligned (Maxwell, Stuenkel & Saylor 2007; Molter 1979).
The study was also assessing how a PFCC intervention could impact on the nurses. To develop this aspect of the study the person-centred nursing framework, was examined and elements drawn on (McCormack & McCance 2006).

2.10.3 McCormack and McCance's person-centred nursing framework

McCormack and McCance's person-centred nursing framework (McCormack & McCance 2006) construct with an explanation for each construct is shown in Table 2.7.

Table 2. 7: McCormack and McCance's person-centred framework

Construct	**Explanation**
Pre-requisite	Attributes of the nurse including: • professionally competent, • developed interpersonal skills • commitment to the job • clarity of belief and values • knowing 'self'
Care environment	Six elements that include: • appropriate skill mix • shared decision making systems • effective staff relationships • supportive organisational systems • power sharing • potential for innovation and risk taking
Person-centred	Five elements relating to delivering care: • working with patient's beliefs and values

Construct	Explanation
processes	• engagement • sharing decision making • having sympathetic presences • providing for physical needs
Person-centred outcomes	Four elements: • satisfaction with care • involvement with care • feeling of well-being • creating a therapeutic culture

(McCormack & McCance 2006)

This framework is guided by the SPO model (Donabedian 1988) and has elements that correspond with the principles of person-centred care (Picker Institute 2008). The use of elements from the three models for this study enabled consistency and integration of ideas. McCormack and McCance reported that adopting a person-centred approach to nursing was holistic, reduced nursing anxiety and promoted teamwork (McCormack & McCance 2006). This supported the aims of this study. It was perceived that nurses in ICU experience more stress and the study aimed to reduce stress levels, as well as, provide a more holistic approach to the care of the ICU patient (McCarthy, Power & Greiner 2010).

In this study the pre-requisite of person-centred care (McCormack & McCance 2006) that aligns with the *structure* of the SPO model (Donabedian 1988) was nurses with well-developed communication skills, that were clinically competent and able to educate and support families to deliver passive exercises.

The study used an innovative approach to PFCC and examined how families of unconscious patients could assist with passive exercises, which aligned with the *process* component of the SPO model (Donabedian 1988). By partnering with the family in providing for physical needs which was the administering of the passive exercises, the aim was to improve *outcomes* by meeting the needs of the family.

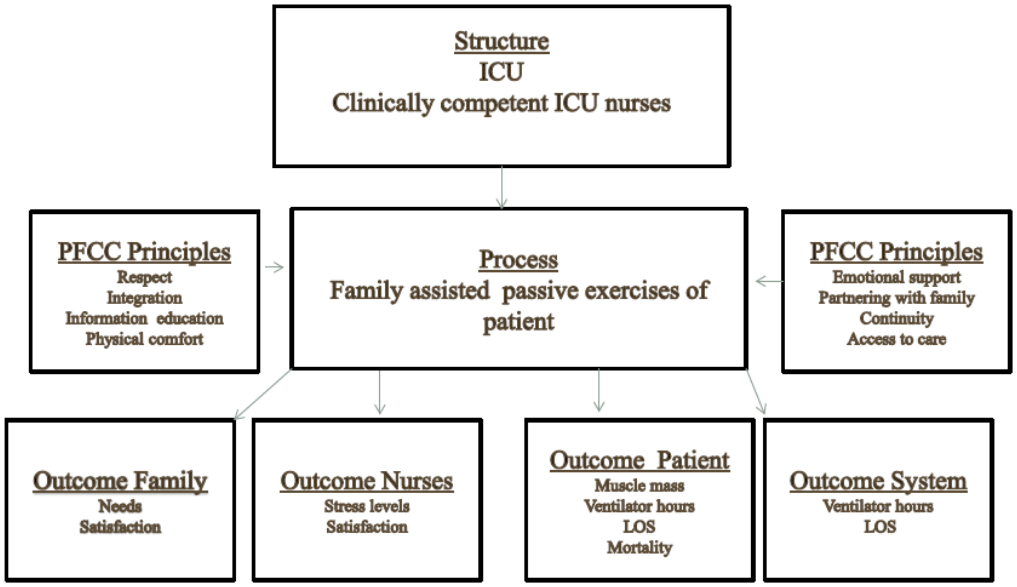
2.10.4 The study's theoretical framework

The purpose designed theoretical framework for family assisted passive exercising in ICU (Figure 2.3), integrates the SPO quality model (Chaboyer, McMurray & Wallis 2010; Donabedian 1988), with patient-centred care principles (ACSQHC 2010; Picker Institute

2008) and McCormack and McCance's person-centred nursing framework (McCormack & McCance 2006).

There are three layers in the theoretical framework for family assisted passive exercising in the ICU. The first layer of the diagram carries the *structure* element of the SPO model. The element of *structure* is depicted to cover the ICU care environment and nursing practices, in keeping with the person-centred nursing framework (McCormack & McCance 2006), it recognises the relationship between a patient's family and a patient's nurse is an essential requirement of PFCC (Mitchell et al. 2009)

Figure 2. 3: Theoretical framework for family assisted passive exercising in ICU



The second layer of the diagram places family assisted passive exercise as the *process* element in line with the SPO model. The process of passive exercise is shown to interact with structure along the eight domains of the Picker Institute (2008) framework.

The third layer of the diagram presents the *outcome* measures for the family, nurses, patient and healthcare system. The *outcomes* for the family were measured by needs met and satisfaction. The *outcome*s for the nurses were measured by assessing stress levels. The *outcomes* for the patient were examined by measuring their muscle mass, ventilator hour, length of stay and mortality. The *outcomes* for the healthcare system also used the measure of ventilator hours and length of stay.

The combined framework although innovative needs further validation as a tool. The challenge for all healthcare providers is to have a framework that is sustainable when the study period is completed and replicable for use in other settings. Although there are some common requirements for PFCC (Picker, 2008; Ogden, Barr & Greenfield 2017) different contexts will have unique challenges and requirements that may not conform to defined principles. Although this model was tailored for the local environment, it is still to be tested in other settings. What has been identified as a limitation of the theoretical framework for family assisted passive exercising in ICU is, the limitations of each of the models used and the impact that this may have on the sustainability of the model. For example: the challenge for the SPO model is the difficulty in establishing the relationships between all the elements (Liu et al. 2011); on further review of the literature McCormack and McCance's person-centred nursing framework although a landmark study, has not been widely replicated by others.

2.11 Conclusion

This chapter has presented the interrelated way of how the PFCC focus for the study evolved, the emergent iterative approach was used to search the literature and together this led to the development of the research questions and purpose-designed research framework. The examination targeted what has previously been studied in relation to family assisting with care in ICU, with a focus on families assisting with passive exercising of their unconscious relatives. Additionally, the implications of PFCC and families assisting with care on the

elements of the families, nurses, patients and healthcare system were considered. This literature analysis has demonstrated that further research is warranted in relation to families assisting with the care of their unconscious relatives in the ICU, as there is conflicting evidence in relation to the usefulness and efficacy of it.

The next chapter describes and justifies the research design for the study, as well as its limitations. It gives an overview of the setting and the sampling process for all participants as well as the choice of survey instruments.

Chapter 3 Research design and study instruments

3.1 Introduction

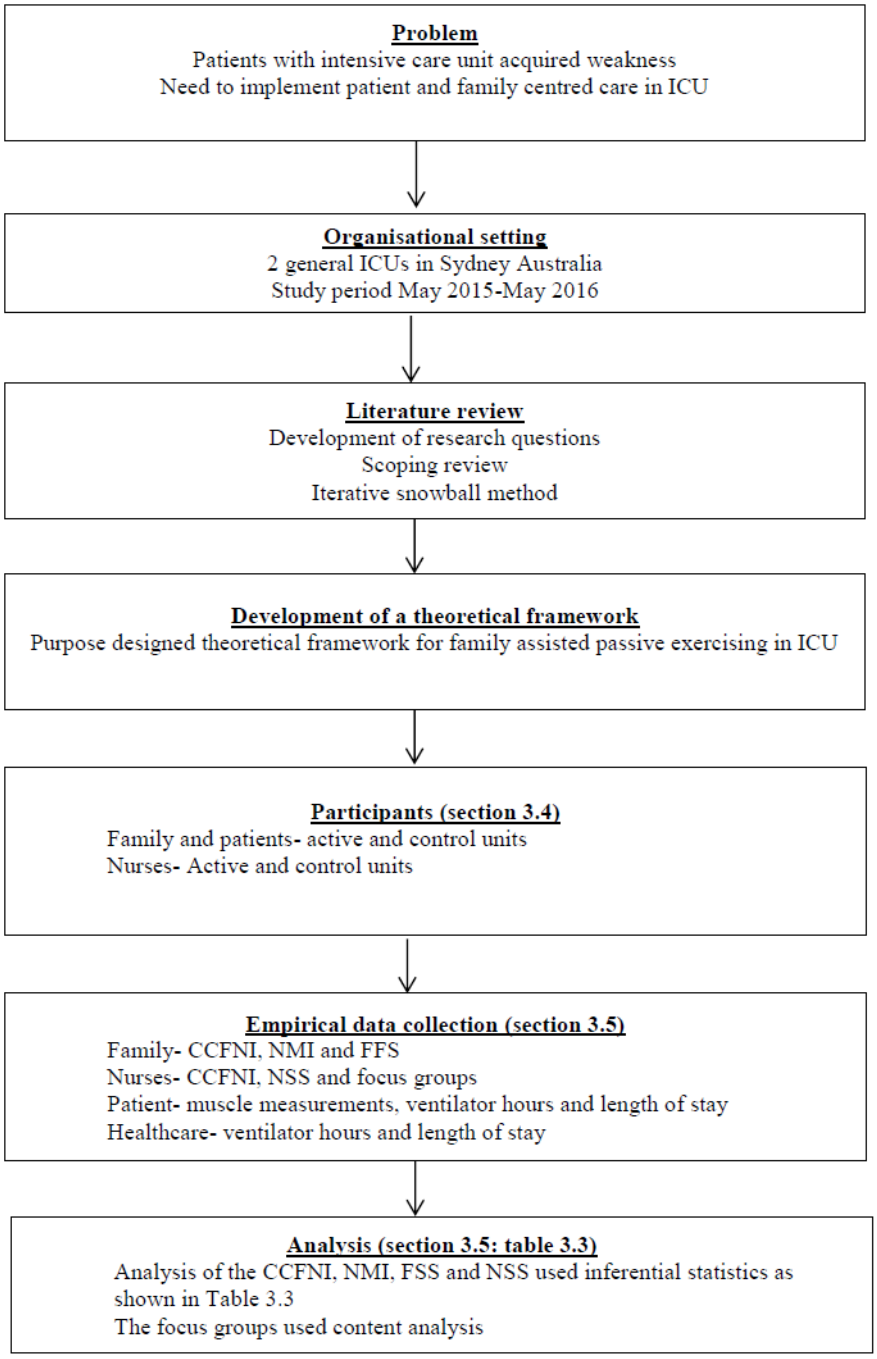
Chapter 2 presented the literature review, the focus of which was PFCC in ICU. It examined what has previously been studied in relation to families assisting with care, with a focus on families assisting with passive exercising of their unconscious relatives in the ICU. The implications of PFCC and the intervention of passive exercising for the elements of the families, nurses, patient and healthcare system were discussed in the context of the theoretical framework for family assisted passive exercising.

With this intention this chapter is structured as follows. First, figure 3.1 shows all parts of the study and their sequencing. Section 3.2 presents the research design and the justification of the methodological choice as well as its limitations. This is followed by an explanation of the study setting and the staffing model of the ICU (section 3.3). The sampling and recruitment of the patient, family and the nurses are explained (section 3.4). Section 3.5 presents the study instruments for the families, the nurses, the patients and the healthcare system. The three study phases are presented in section 3.6: first, the scoping phase, which was the preparation phase and includes, the ethics process, the data management and confidentiality process, the development of the information sheets and consent forms; secondly, the process phase, which explains the passive exercises and the education process for the nurses in relation to them; and finally, the outcome phase, which involved data gathering and analysis.

3.2 Research design

PFCC studies in the literature were examined to inform the study design (Azoulay et al. 2003; Bailey et al. 2009; Burr 1998; Kinrade, Jackson & Tomnay 2010; Maxwell, Stuenkel & Saylor 2007; Nolen & Warren 2014). The aim of many of these studies was to understand the needs of families in the ICU setting. This study not only wanted to understand the needs of family, but also wanted to evaluate a PFCC intervention and the impact this intervention had on family needs, which at the time of the study period in 2015, was limited (Baning 2012).

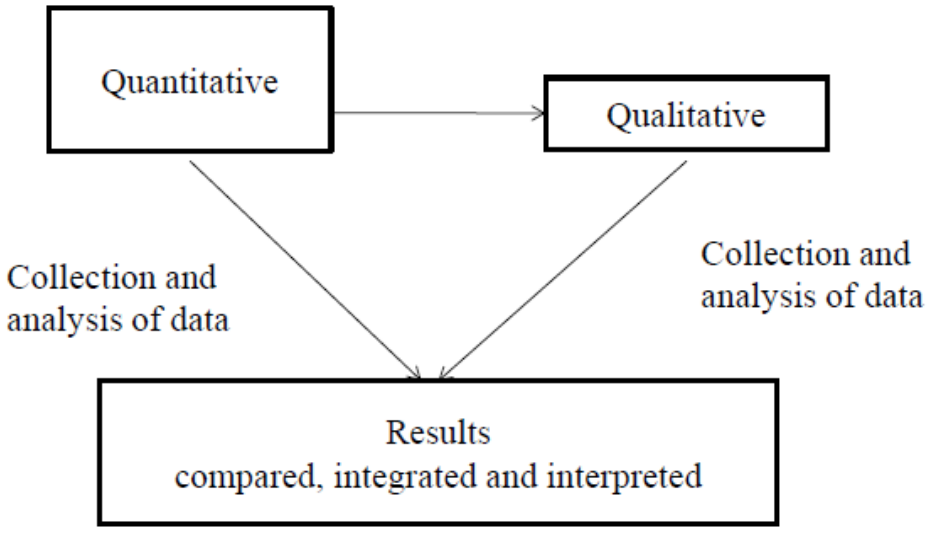
Figure 3. 1 Sequencing of the study



3.2.1 Justification of the methodological choice

The research design incorporated a prospective (Azoulay et al. 2003; Steel et al. 2008), comparative (Baning 2012; Rippin et al. 2015), interventional (Baning 2012) approach to data collection to address the research aim and questions. The aim was to examine the experiences of two cohorts of patients and their families through assessing if the intervention of passive exercising had any impact over the course of the patient's admission. The focuses of the assessments were families, nurses, patients and healthcare system. This thesis has taken a philosophical approach of pragmatism, an approach where research questions are investigated for pragmatic answers (Creswell 2014; Cornish & Gillespie, 2009). This approach was driven by the needs at the research site. At the time of commencing the study little was known about ICUAW and its relationship with PFCC. Hence, the explanatory design adopted to investigate this significant practice problem in the ICU context. Data collection was triangulated in this research, as per the explanatory mixed methods research design (Creswell et al., 2010) and as shown in Figure 3.2 using a combination of quantitative and qualitative research methods.

Figure 3. 2: Visual diagram of the study design



(Atif, Richards & Bilgin 2013)

The quantitative approach was the dominant aspect of the study, using the CCFNI, NMI, mNSS, muscle measurements and study specific instruments to gather the data. The qualitative approach was focus groups with the direct care nurses from each of the study units, and the nurse educators and managers from both units combined. The instruments chosen will be discussed further in section 3.5

The underlying logic of mixing the data sources is that neither quantitative nor qualitative methods are sufficient in themselves to capture the trends and details to answer the research question (Fetters & Molina-Azorin 2017; Onwuegbuzie & Collins 2007).When used in combination, both quantitative and qualitative data yield a more complete analysis, and they complement each other (Burr 1998; Creswell, Fetters & Ivankova 2004; Fereday 2006; Fetters, Curry & Creswell 2013; Fetters & Molina-Azorin 2017). For example, understanding the nurses' perceptions of ICU family needs and the impact of the passive exercise required greater exploration of the insights of the direct care nurses. Hence, focus groups with nurses complemented the surveys and other data collection measurements.

3.2.2 Limitations of the research design

This was a single site study, however due to the scale of the services, with multiple units and a mix of medical and surgical patients; it was considered comparable to other units across Australia and internationally.

As already observed above, the quantitative data were the dominant aspect of the research design. The reason for this was pre-test it was considered to be possibly too traumatic for the family members to be interviewed or to be involved in focus groups. Post-test, literature was discovered in relation to participation of bereaved families in research (Kentish-Barnes et al. 2015). This research recognised, that families found participation in research beneficial, by giving them an opportunity to talk about their ICU experience and to give meaning to the end- of-life process and to feel that someone cared about them (Kentish-Barnes et al. 2015). With this knowledge, involving families with, either interviews or focus groups would have given a more complete picture of the impact of the study on the families and the patients. This understanding is the basis for a recommendation for future research.

Limitations around the sample size for the families and patients are acknowledged and discussed in section 3.4.1.1.Namely, the practical limitations of recruiting in a specific period

during doctoral study; the attrition of some of the families and patients and the use of the active and control units.

3.3 Setting and ICU staffing model

As outlined in Chapter 1, this study was conducted in a publicly funded, tertiary and quaternary referral teaching hospital in Sydney, Australia between May 2015 and May 2016. The hospital provides a range of medical and surgical services, is a major trauma centre with an Emergency Department (ED) providing 74,645 occasions of service in the 2015-16 financial year (RPAH Strategic Plan 2013-18). There are four ICUs in the hospital and in 2013 they had, in total, 3456 admissions. The two general ICUs where the study was conducted are co-located with a cardiothoracic and a neurosurgical ICU providing a total of 48 beds. The active unit has 13 beds and the control unit 14 beds.

Admission of patients to the active and control units depends on a daily alternating roster, as well as availabity of beds and respiratory ventilators in the units. Patients present with a variety of illnesses and disease processes, some planned post-operatively from theatres and others unplanned such as post-cardiac arrest from the ED and the inpatient units. This means that the cohorts of patients in both units are very similar and therefore, they were considered suitable for a comparative study.

Patients are managed in the units by medical intensivist specialists and they are co-managed by a variety of medical and surgical teams. There is 24-hour medical cover provided by rostered junior and senior medical staff. Although discreet units, managed by nursing unit managers (NUMs) with their own clinical nurse educators (CNE), the staffing and budget is managed centrally by a nurse manager and there is one shared clinical nurse consultant (CNC). The nurses range from: novices who have just completed their internship year at the hospital; those on a two year rotational introductory ICU nursing training course; to senior nurses who have a post- graduate degree in critical care nursing. Staffing depends on the acuity of the patient's medical condition, but at a minimum if a patient is requiring mechanical ventilation they have a dedicated nurse looking after them.

For the study it was decided to make an active unit, where family members performed the passive exercises on the patient and a control unit, where the patients received standard care

with the nurses performing the passive exercises. This was to ensure that the nurses in each unit were clear about the process and their responsibilities in relation to the study. The decision on which unit was the active unit, was based on previous experience of one of the nurses from the active unit having shown a desire to implement a similar project previously.

3.4 Sampling and recruitment

The participants in this study included the ICU patients and their families and ICU nurses. The sampling and recruitment for each group are expanded on below.

3.4.1 Sampling and recruitment of ICU patients and families

Recruitment of the patients and their families occurred from May 2015 to May 2016. Recruitment of the patients and families was based on medical suitability of the patient. Medical suitability was determined with the assistance of the ICU experts (discussed in the section 3.6.1 of this chapter) and based on previous ICU studies (Morris et al. 2008; Winkelman et al. 2012). The inclusion and exclusion criteria are presented in Table 3.1.

To expand on these criteria, the patient had to be: receiving mechanical ventilation, and anticipated to require this for at least three days (Morris et al. 2008); and, unconscious with a Glasgow Coma Score (GCS) of less than eight. The GCS tool was initially developed for patients with traumatic or other brain injury (Teasdale & Jennett 1974). It assesses the patient's level of consciousness on their best verbal and motor response and whether they can open their eyes. The GCS has become a universal determinant of level of consciousness used in all the ICUs and Emergency Departments in Australia. It is used for multiple medical and surgical conditions, and is a practical method for assessment of impairment of conscious level in response to defined stimuli (Tanaka et al. 2014; Barlow 2012; Matis & Birbilis 2008). It is also used as clinical predictor of weaning and extubation in Australian and New Zealand ICUs (Rose & Presneill 2011). At the study site this is used in conjunction with the Richmond Agitation-Sedation Scale (RASS). The RASS is used in mechanically ventilated patients to avoid over or under sedating them. Although this was recorded on the patients in the study this was not used as a determinant for the study. GCS of less than eight regardless of sedation was the target group.

Table 3. 1: Inclusion and exclusion criteria for the patient

Criteria	Inclusion	Exclusion
Consciousness	Glasgow Coma Score < 8	Glasgow Coma Score >8
Mechanical Ventilation and anticipated for 3 days	Yes	Breathing spontaneously
Manual muscle test	0-2	3-5
*P/F Ratio: Partial pressure to inspired oxygen	>100	<100
*Fio2: Fraction of inspired oxygen	<60%	>60%
*PEEP: Positive end-expiratory pressure	<10cm H20	>10cm H20
*MAP: Mean Arterial Pressure	60-100 mmHg	<60mmHg >100mmHg
HR: Heart rate beats per minute	50-125	<50 >125
*Spo2: Blood oxygen saturation level	>88%	<88%
Family	Present	Not present
Other medical criteria		Extra corporeal membranous oxygenation Body mass Index>30 Pelvic Exenteration Multiple trauma Patients for palliation

The patient also had to have a manual muscle test (MMT) score of 0-2, indicating that they would have limited movement of their limbs (Morris et al. 2008) and make them more susceptible to muscle wasting and weakness. The patient had to be clinically stable and this was determined by the physiological parameters shown in Table 3.1 (Morris et al. 2008; Winkelman et al. 2012). If the patient was not clinically suitable initially or the family member was not initially present this did not preclude them from being enrolled at a later time, if they subsequently met the study criteria.

There were conditions that excluded patients from being considered for the study. This included patients that were critically unwell, as identified with vital signs outside the defined ratios as shown in Table 3.1 (Winkelman et al. 2012). Other patients that were excluded were those: with trauma related multiple injuries; that had had pelvic exenteration surgery; who were receiving extracorporeal membrane oxygenation (ECMO). All of these patients were deemed unsuitable due to either, the extent of the injury or surgery, and the associated equipment that could get dislodged with the intervention. In consideration of workplace

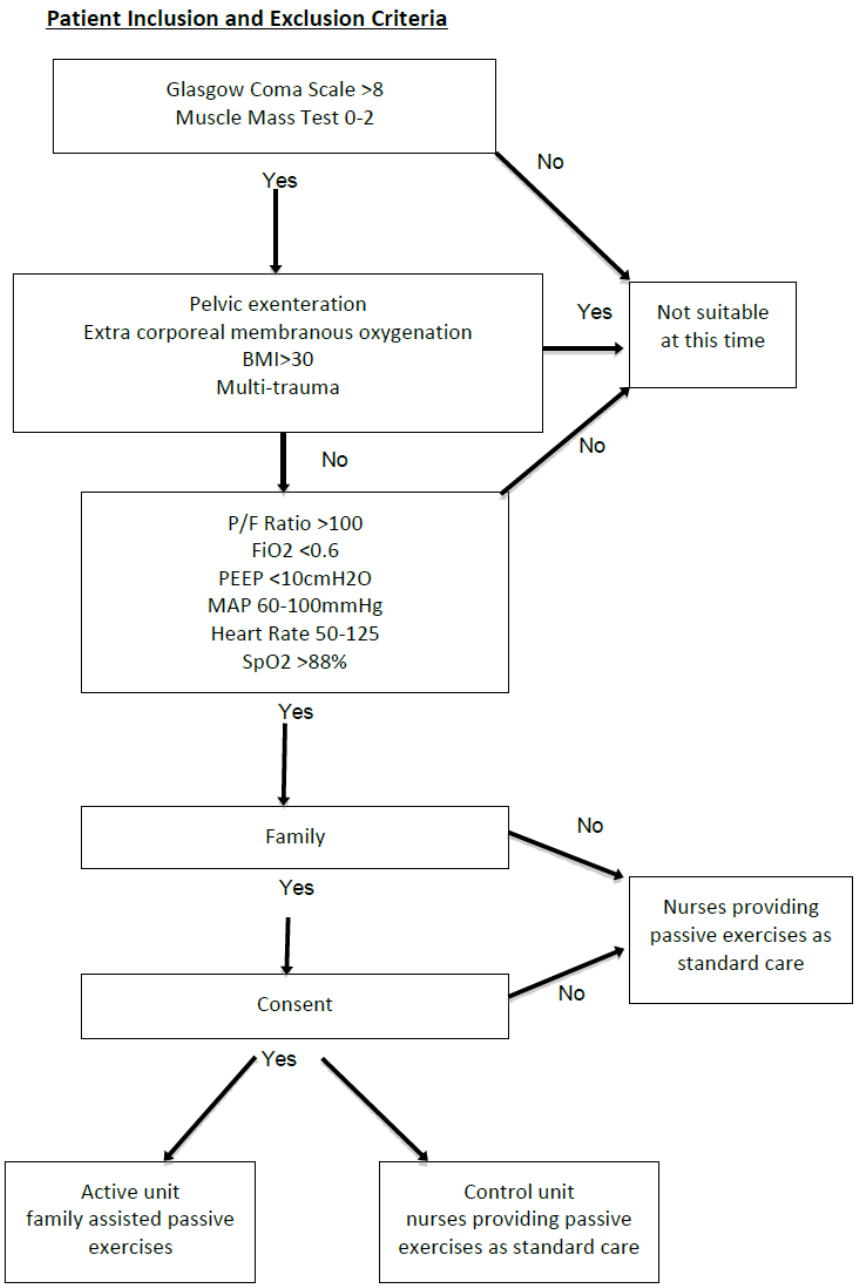
health and safety (WHS) issues, patients with a body mass index (BMI) of greater than 30 were also excluded.

Consideration was given to using the Acute Physiology and Chronic Health Evaluation (APACHE) II score tool (Knaus et al. 1985) to determine which patients to include and exclude in the study. This tool has been used extensively in the adult ICU setting and measures severity of illness and is a predictor of risk, of the patient's death (Azoulay et al. 2003; Lilly et al. 2011; Morris et al. 2008; Nielsen et al. 2019). The tool measures over a twenty-four hour period after admission: patient age; chronic health conditions; diagnosis; source of admission; physiology; blood investigation levels; blood gases and GCS. The score given is an integer from 0-71 based on each of the parameters. A higher score is indicative of more severe disease and higher risk of death for the patient. However, at the time of the study, the tool was not available at the study site.

The ICU experts also assisted with the development of a screening tool (Appendix 2) and a flowchart which included the inclusion and exclusion criteria to assist with screening and determining suitable patients for the study (Figure 3.2). Using these tools, all patients that were admitted to the acute and control units were screened on admission and then daily by one of the research team to see if they were medically suitable to be enrolled for the study. This was done in collaboration with the direct care nurse looking after the patient. Patients were not randomised into the units. If they were suitable to be in the study, the unit they were admitted to was the determinant of whether they had the intervention or standard treatment.

Patients who met the eligibility criteria and who had family members in attendance determined the families that were approached in both the active and control units to participate. The definition of family for this study was anyone over the age of 18 years that had a significant relationship with the patient, this included spouse, parents, children, siblings and friends (Kinrade, Jackson & Tomnay 2010; Maxwell, Stuenkel & Saylor 2007; Obringer, Hilgenberg & Booker 2012; Warren 1994).

Figure 3. 3: Flowchart to determine patient suitability for inclusion in the study



The family member was given an explanation of the study by the senior nurse, as well as an information sheet which was individualised for each unit (Appendices 3 and 4). The families were asked to reflect on this information and there was no coercion to participate. These families were then followed up by a senior nurse as to whether they wanted to participate.

Once the families agreed to participate, they were given a consent form to complete (Appendix 5) as well as the exercise pamphlets. The family information pamphlets, in keeping with the NSW Clinical Excellence Commission, used plain language to ensure it was comprehensible and coherent to the families. This was guided by using the *Step by Step Writing Guide for Developing Plain English Consumer Information* (Illawarra Shoalhaven Local Health Disctrict 2013).

The information sheets (Appendix 3 and 4) were developed for the active and the control units. The information sheets explained the study and its anticipated benefits. They advised the families that participation was voluntary and that there were no foreseeable risks. The process of confidentiality was explained and families were assured that theirs and the patient's information would be de-identified. The ethics and complaint process was outlined and families were advised that there were no financial costs to them and that they would not be receiving any payment.

3.4.1.1 Sample size

To determine the sample size of patients and families that needed to be recruited for the study, the data were reviewed from the ICUs EMR for the calendar year 2013. In that year the active and control units had combined patient admissions of 2001 individuals. The sub-cohort within this population with an admission of greater than three days was approximately one quarter (n=447). The group that met the research criteria of being unconscious and intubated with the necessary muscle weakness score was one tenth of the sub-cohort (n=40). Based on these figures and as determined by the National Sample Size Calculator (ABS 2015), a minimum sample of 30 participants was required (Table 3.2.).

Table 3. 2: Sample size determinant using the National Statistical Service's sample size calculator

Sample Size Determinant	
Confidence Level	95%
Population Size	40
Proportion	0.09
Confidence Interval Upper Lower	0.05 0.14 0.04
Standard Error	0.03
Relative Standard Error	28.35
Sample	30

The family and patient cohort were purposively selected so that the research questions could be answered and was appropriate for the field of study and is similar to other peer reviewed studies in relation to PFCC and the use of the CCFNI (Gentry et al. 2014; Kinrade, Jackson & Tomnay 2010; Maxwell, Stuenkel & Saylor 2007; Mitchell, Chaboyer, Burmeister & Foster 2009). It is acknowledged that that the sample size for this study was limited by the practical limitations of recruiting in a specific period during doctoral study; the attrition of some of the families and patients, and the use of the active and control units. However, the small sample size did not have an extreme distribution and could logically support the statistical tests to answer the research questions as shown by the analysis in Appendices 13-18.The use of an active and control unit for the study appeared to be unique and has added to the literature. These factors will be presented when the study is published.

Quantitative data were obtained from the families using the CCFNI, NMI (Appendix 6) and the Family Feedback Survey (FFS). These were explained and given to them by the senior nurse enrolling them into the study. Quantitative data were obtained from the patients' EMR at post-test. Further information on the instruments is given in Section 3.5

3.4.2 Sampling and recruitment of ICU nurses

The role of the nurses in the study was to undertake the exercises in the control unit or educate and facilitate the families to do the exercises in the active unit. All nurses that were actively involved with direct nursing care of the patients in the active and control units were invited to participate. This method of sampling, known as census sampling (Fricker 2008; Statistics 2018), also considered participants years of nursing, years nursing in ICU so as to gather a wider variety of opinion and to provide an accurate representation of the nursing groups (Mays & Pope 2000; Onwuegbuzie et al. 2009) This approach was used because: there had been no previous PFCC studies at the study site, and therefore it was an opportunity to canvas all the nurses in the active and control units in relation to their perception of family needs, and to determine if a PFCC study would have any impact on nursing stressors or satisfaction. Quantitative data using the mNSS (Appendix 9) were obtained from surveying the nurses pre-test in April 2015 and post-test in May 2016. Further information on the instrument is given in Section 3.5.

Qualitative data were obtained from three focus groups held with the nurses post-test in May 2016. The focus groups were held with the RNs of the active and control units, and a separate group which combined active and control unit managers and educators. Participants for the separate active and control units focus groups were chosen using convenience sampling (Bloomer et al. 2013; Lakanmaa et al. 2015). This was principally driven by the availability of the nurses on the day of the focus group to be released from patient care. The groups were convened in the afternoon when there was maximum staff on duty in the ICUs. All of the attendees were invited by letter (Appendix 10) and email to participate. They then signed a consent form (Appendix 11) agreeing to participate and to having the sessions recorded.

3.5 Instruments

The research design as discussed in section 3.2 used a number of instruments to answer the research questions. These are summarised in Table 3.3.The instruments chosen were based on their relevance to the theoretical framework and as can be seen, the quantitative data has taken the dominant role in this research.

Table 3. 3: Research questions and instruments used to answer them

Section	Research question	Method	Instrument	Participants	Timeframe	Purpose	Analysis
3.6.1	Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for families?	Survey	CCFNI	Families of patients of the active and control units	On admission of family member to ICU pre-test	To determine perception of needs of family members pre-test	Non-parametric Mann-Whitney U test
		Survey	NMI	Families of patients of the active and control units	On discharge of family member from ICU post-test	To determine whether the identified needs of family members pre-test were met and if the outcomes differed between the active and control units	Non-parametric paired test Wilcoxon signed rank test compared the results of the CCFNI to NMI
		Survey	CCFNI	Families of patients of the active and control units compared to nurses of the same unit	Pre-test	Comparison of families and nurses perception of family needs pre-test to see if the perceptions of families' needs were the same	Non-parametric Mann-Whitney U test
		Survey	CCFNI	Families of patients of the active and control units compared to nurses of the same unit	Post-test	Comparison of families and nurses perception of needs post-test to see if the intervention changed nurses perception of families' needs	Non-parametric Mann-Whitney U test
		Survey	FFS	Families of patients of the active and control units	Post-test	To determine overall rating by families of	Non-parametric Mann-Whitney U test

Section	Research question	Method	Instrument	Participants	Timeframe	Purpose	Analysis
						their experience in the ICU and to see if there was any difference between the active and control units	
		Focus groups	Purpose designed tool	1.Nurses of the active unit 2. Nurses of the control unit 3. Managers and educators of the active and control unit combined	Post-test	To investigate the perceptions of the nurses in relation to elements under inquiry	Thematic analysis
	Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for nurses?	Survey	mNSS	Nurses of the active and control units	Pre- and post-test	To determine what items and factors nurses found, most and least stressful	Non-parametric Mann-Whitney U test
						To determine whether a PFCC intervention could improve nurses' workplace stress and satisfaction	Means analysis
						To determine whether there was a difference in stress levels depending on years nursing and years nursing in ICU	Non-parametric rank correlation

Section	Research question	Method	Instrument	Participants	Timeframe	Purpose	Analysis
	Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for nurses?	Focus groups	Purpose designed tool	1.Nurses of the active unit 2. Nurses of the control unit 3. Managers and educators of the active and control unit combined	Post- test	To answer elements of inquiry not necessarily answered by the mNSS	Thematic analysis
	Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for patients and the healthcare system?	Clinical evaluation	Ultrasound measurement and tape measure	Patients in the active and control units	On admission during the ICU admission	To determine whether passive exercises, prevented muscle wasting and whether there was any difference between the unit where family delivered the exercises compared to the unit where direct care nurses delivered the exercises	Non-parametric Mann Whitney U test Paired Wilcoxon signed rank test
		Secondary data analysis. Ventilator hours, length of stay ICU and hospital and mortality	Purpose designed tool and ICU EMR	Patients in the active and control units	Post-test	To determine whether the intervention improved any of the patient and healthcare outcomes	Non-parametric Mann-Whitney U test

3.5.1 Instruments to measure family outcomes

Outcomes of family needs and satisfaction were measured using the modified 30-item version of the CCFNI (Bailey et al. 2009; Baning 2012; Maxwell, Stuenkel & Saylor 2007; Mitchell et al. 2016; O'Neill-Norris & Grove 1986), the NMI (Maxwell, Stuenkel & Saylor 2007; Nolen & Warren 2014; Warren 1994) and the FFS(NHS 2012, 2014). The version of the CCFNI and NMI used in this study are located at Appendix 10. The authors were written to, seeking permission to use these instruments.

3.5.1.1 CCFNI and NMI

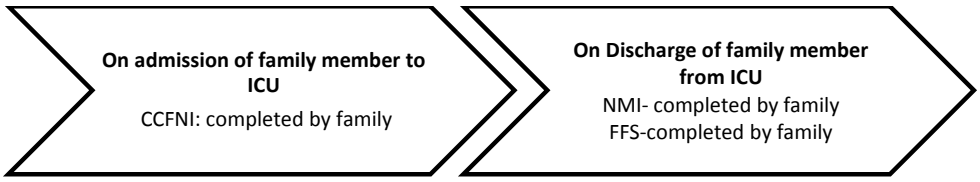
The CCFNI (Kinrade, Jackson & Tomnay 2010; Leske 1991; Molter 1979) and the modified CCFNI (Bailey et al. 2009; Baning 2012; Maxwell, Stuenkel & Saylor 2007; O'Neill-Norris & Grove 1986) categorise family needs into five domains that are: information; proximity to the patient; assurance; support and comfort. These domains, and therefore the instrument, align with defined PFCC principles of the theoretical framework (ACSQHC 2017; Picker Institute 2008; Rathert, Wyrwich & Boren 2012). Each of these domains are made up of individual items of need and participants are asked to rate the importance of each need. This is done using a four-point Likert type scale (Kinrade, Jackson & Tomnay 2010; Kuster, 2017; Maxwell, Stuenkel & Saylor 2007; Mitchell et al. 2019; Nolen & Warren 2014), with one being *not important*, two *slightly important*, three *important* and four *very important.* Means are obtained for both the items and domains. Each item can score a maximum of 4.0 the domains score an aggregate of the items. Each domain has a different mean value as they have a different number of items. The maximum score for the domains are: support 24.0; comfort 8.0; assurance 28; information 24 and proximity 36.

Warren (1994) in her study identified that as well as identifying the needs of family, it was important to assess whether family needs were met. She developed with the permission of Molter and Leske, the NMI (Nolen & Warren 2014; Warren 1994). This instrument has the same domains which align with the CCFNI, but the participants are now asked if their needs are met. The instrument also uses a four-point Likert Scale (Kinrade, Jackson & Tomnay 2010; Kuster 2017; Maxwell, Stuenkel & Saylor 2007; Mitchell et ql. 2019; Nolen & Warren 2014) with one being *never met,* two *sometimes met*, three *usually met* and four *always met.*

Both the original and modified version of the CCFNI instrument has been used extensively over many years both in Australia and internationally, to measure the effects of PFCC studies (Bailey et al. 2009; Baning 2012; Kinrade, Jackson & Tomnay 2010; Maxwell, Stuenkel & Saylor 2007; Mitchell et al. 2016). The CCFNI has been examined and shown to have test-retest reliability and construct validity (Bijttebier et al. 2000; Leske 1991; Nolen & Warren 2014; van den Broek et al. 2015; Wasser et al. 2001). The reliability of the NMI has been established (Cronbach's alpha of .93) (Maxwell, Stuenkel, and Saylor, 2007;Baning 2012). The longevity of the instruments underpins the recognition that they are good diagnostic instruments (Baning 2012; Kinrade, Jackson & Tomnay 2010; Maxwell, Stuenkel & Saylor 2007; Roberti & Fitzpatrick 2010). Prior to ethics approval for the study, 19 random families from the active and control unit were approached to check the usability of the instrument at the study site. The feedback was positive for ease of use.

Importantly the CCFNI has been used to assess family needs against the nurses' perception of family needs (Maxwell, Stuenkel & Saylor 2007; Mitchell et al. 2016). Previously this assessment has shown asymmetry between the two groups, with nurses not fully understanding what families need (Blanchard & Alavi 2008; Kinrade, Jackson & Tomnay 2010; Kosco & Warren 2000; Maxwell, Stuenkel & Saylor 2007; O'Neill-Norris & Grove 1986). There was a perception by the research team that this was also the case at the study site and was the reasons that this instrument was chosen.

Figure 3. 4: Instruments and timelines for families



As shown in Figure 3.3 the CCFNI was completed by the family when their relative was admitted to the ICU, this was to determine what families identified as their needs pre-test. Post-test when their family member was discharged from the ICU they completed: the NMI to determine if their needs as identified by the CCFNI were met and the FFS (section 3.5.1.2)

to gauge their overall satisfaction.

The nurses of the active and control units were surveyed using the CCFNI pre- and post-test. The intention of this was to determine whether the nurses' perception of family needs aligned with what families identified as their needs; and whether there was any changes identified from pre- to post-test in this perception following the intervention of family assisted passive exercising (Kinrade, Jackson & Tomnay 2010; Maxwell, Stuenkel & Saylor 2007; O'Neill-Norris & Grove 1986).

The data from the CCFNI and NMI generated by the families were analysed using descriptive and inferential statistics. As the sample size was small and it was not clear that data were normally distributed, analysis was conducted using non-parametric analysis (Nahm 2016).

Non-parametric inferential statistics tests are known to manage small sample size well, as these tests do not rely on the condition of normally distributed data (du Prel et al.2010). It should be noted that the reporting of mean in this thesis served the purpose of easy understanding of quantitative results. Application of non-parametric Mann-Whitney U test ensured the data were appropriately analysed, using the mean rank rather than mean value. Moreover, none of the data from the sample of family had extreme distribution to distort the results of the non-parametric tests. As shown in Appendices 13 to 18 the reported curves on the histograms and the Kurtosis value on CCFNI, NMI and FSS provide evidence of this claim (Byrne 2016). The claim of non-extreme distribution of the family data is valid across the active and control units, with the reported Kurtosis index being less than 7 (Byrne 2016). Wherever applicable, as shown in Appendices 13 to 18, the non-extreme distribution of data were also evident in the pre- and post-stages. Therefore, the application of statistical analysis has been appropriate to answer the research questions on assessing the influence of the intervention on family.

The family results of the CCFNI and NMI were analysed using paired Wilcoxon signed-rank test; the comparison of the family and nurses and nurses compared to nurses' were analysed using the Mann-Whitney U test. The complete results are presented in Chapter 4 and a detailed discussion around the findings in Chapter 7.

3.5.1.2 Family Feedback Survey

The FFS was developed to gauge the overall satisfaction of the family of the patients in ICU. The instrument was scored on a scale of 0-100 and was based on the National Health Service (NHS) England, Friends and Family Test (FFT) (NHS 2012). The inpatient FFT was introduced in all English acute hospitals in April 2013. The aim was to provide a simple metric that, when combined with follow-up questions, could be used to drive cultural change and improve the quality of care (NHS 2012). The reliability and validity of the tool has been questioned in that low levels of response rates can result in bias (Skillen 2019); and it is considered flawed as a performance measure (Picker 2014); however, its focus on people's experiences is supported (Picker 2014), which was the purpose for its use in this study, hence its use.

This survey was collected from the family when the patient was discharged from the ICU (Figure 3.3). For this study the opening statement was: *We would like you to think about your recent experience of our service* followed by the question, *how likely are you to recommend our service to friends and family if they needed similar care or treatment?* The results of the FFS were analysed using non-parametric testing with the Mann-Whitney U test and are presented in Chapter 4.

3.5.1.3 Nurses' focus groups

As discussed in section 3.4.2 of this chapter, focus groups were held with the nurses. The purpose of these focus groups was to first gain greater insight into the nurses' perceptions of ICU families' needs; and secondly their perception of the impact of the family assisting with passive exercise on the family, patient, nurses and healthcare system. The choice of focus groups was first, to canvass as many nurses as possible in the most time efficient way. Second, the structure of focus groups allowed the participants to study the issues collectively and for the researcher to be more observant. This was seen as appropriate given that team work is a focus in the ICU setting. It is however recognised that this can allow quieter members of the team to be passive in discussions and requires the skills of the moderator to ensure that all participants are afforded equal time to speak (Lincoln & Guba 1985, Nyumba et al. 2017).

The literature was examined for interview questions for theses focus groups. As there was no previous study with family assisting with passive exercises in the ICU, a purpose designed semi-structured interview instrument was developed (Appendix 10). This was in collaboration with the ICU experts and after discussion with the supervisory team.

The three focus groups were each conducted over one hour, in the ICU tutorial room. Each group had no more than seven participants, as groups of this size have been identified as less threatening and more conducive to discussion and gathering of information (Bloomer et al. 2013; Onwuegbuzie et al. 2009). Prior to the discussions commencing, the groups were given a verbal overview of the study. All participants were cognisant of the study.

The groups were taped with the consent of the participants and transcripts made of the sessions. A guided discussion was facilitated with the researcher as the moderator, assisted by the CNC for ICU (Onwuegbuzie et al. 2009). The role of the moderator was to facilitate discussion and the CNC encouraged participation by all members of the group ensuring that no one person dominated the group (Onwuegbuzie et al. 2009).

Once the sessions were complete transcript-based analysis was then used as it is reported to be the most rigorous and reliable mode of analysing data (Braun & Clarke 2006; Vaismoradi, Turunen & Bondas 2013). This was a five-step process. First, the recordings were each combined into one text document and uploaded into a text management program (N-Vivo) by the researcher. The text management program was used purely to identify prominent words to support the themes. Second, the text count and the word-cloud that this program generated were reviewed as a whole to gain an understanding of the variety and scope of the responses.Third, the text was examined line-by-line to identify the key points from respondents for each of the questions asked. Fourth, the key points were examined and refined into similar themes across respondents. Fifth, the respondents themes were assessed for areas of convergence and divergence in responses.

It is recognised that there may be limitations with this approach to the analysis. That qualitative research is often criticised for lack of rigour and subject to researcher bias and opinion (Noble & Smith 2015). To address the issue of bias the second to fifth stage of the analysis was done by the researcher and the CNCs for PFCC and ICU, who then compared the results of the analysis. The review findings were then shared with the ICU experts. This

was in keeping with the alternative criteria for demonstrating rigour of, truth value, consistency and neutrality and applicability as proposed by Lincoln and Guba (1985).

3.5.2 Instrument to measure nurses' outcomes

Outcomes of nurses' stress levels were measured using a mNSS and the same focus groups that were used in relation to the families.

3.5.2.1 Modified Nursing Stress Scale

Nurse outcomes were measured using a study specific modified version of the NSS (Gray-Toft & Anderson 1981b; Lim, Bogossian & Ahern 2010; Purcell, Kutash & Cobb 2011; Rolf 1999). The original NSS was a 34-item tool that described potentially stressful situations for nurses in the performance of their duties (Gray-Toft & Anderson 1981b). The items align to seven subscales that consist of the factors of: death and dying; conflict with physicians; inadequate preparation; lack of support; conflict with other nurses; workload; and uncertainty concerning treatment. The NSS uses a four-point Likert Scale (Kuster 2017; McCarthy, Powers & Greiner 2010) with the respondent being able to rank the stressors as; one being *never*, two *occasionally*, three *frequently* and four *very frequently*. It has been tested for reliability and validity (Gray-Toft & Anderson 1981b; Healy & McKay 1999; Lee, Holzemer & Faucett 2007; Lim, Bogossian & Ahern 2010; Suresh, Matthews & Coyne 2012) and used in multiple clinical settings around the world.

The NSS has previously been modified by others to incorporate specific stressors of the area under study, without compromising the reliability or validity (French et al. 2000; Gray-Toft & Anderson 1985). Due to its longevity and adaptability it was the survey instrument of choice. In this study, the question about conflict with a physician as a stressor was removed from the instrument, as there was also a question about criticism by a physician in the instrument. The instrument was modified to incorporate four additional stressful situations which were specific to the intervention of passive exercise in this study. They were whether: teaching, talking, discussing clinical care with family members, or delivering passive exercises to patients caused stress. The question was removed
Permission was sought from the authors of the NSS, in relation to the modifications.

The modified instrument (mNSS) was peer reviewed with the ICU working party, to identify question applicability. Moreover, internal consistency of additional study specific questions was determined using Cronbach's alpha. The Tables 3.4 and 3.5 present the pre-test and post-test results of the combined responses from the active and control units. The results showed a satisfactory level of consistency: pre-test period (n=100; $\alpha = 0.84$) and post-test period (n=80; $\alpha = 0.80$). The Cronbach's alpha results from this study are higher than the cut-off point of 0.7 (Polit & Beck, 2010). The full result of the Cronbach's alpha pre-and post- test on the study specific questions are located in Appendices 20 and 21.

Table 3. 4: Pre-test Cronbach's alpha of the study specific items of mNSS

Item	Mean	Standard Deviation	n=	Cronbach's alpha based on standardised items
Teaching family	2.08	.68	100	.84
Talking to family	2.42	1.01	100	
Passive exercises	1.89	.72	100	
Clinical discussion	2.25	.88	100	

Table 3. 5: Post-test Cronbach's alpha of the study specific items of mNSS

Item	Mean	Standard Deviation	n=	Cronbach's alpha based on standardised items
Teaching family	2.11	.69	80	.80
Talking to family	2.65	.99	80	
Passive exercises	1.89	.61	80	
Clinical discussions	2.42	.88	80	

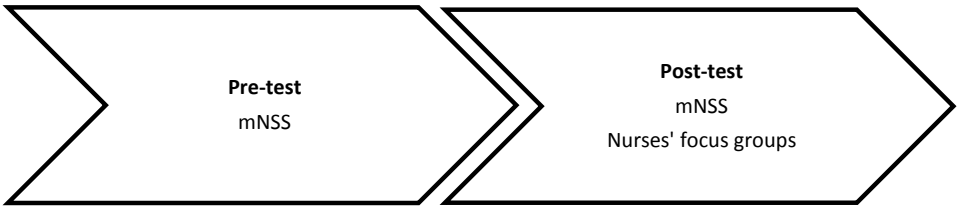
The modified instrument is located in Appendix 11 and has 37 questions. Each of these questions, rated on the Likert Scale (Kuster 2017:McCarthy, Powers & Greiner 2010) with a score of 1-4 provides a potential maximum score of 148. The factors all have different items that comprise their varying scores as shown in Table 3.6.

Table 3. 6: mNSS factors and items maximum scores

	Factor	Items	Maximum score
Factor 1:	Death and dying	Seven items	28
Factor 2	Conflict with physicians	Four items	16
Factor 3:	Inadequate preparation to deal with the emotional needs of patients and their families	Three items	12
Factor 4:	Lack of staff support	Three items	12
Factor 5:	Conflict with other nurses and supervisors	Five items	20
Factor 6:	Workload	Six items	24
Factor 7:	Uncertainty concerning treatment	Five items	20
Factor 8:	Study specific questions	Four items	16

As shown in Figure 3.4 the mNSS was completed at baseline (pre-test) and at conclusion of the study period (post-test). Pre- and post-test results were examined by the individual units and between the active and control units.

Figure 3. 5: Instruments and timelines for nurses



The data from the mNSS were analysed using descriptive and inferential statistics. Non-parametric analysis was with the Mann-Whitney U test. The means of the individual items, as well as the eight factors that the items are categorised into, were analysed to identify what was perceived as the highest and lowest work stressors. The results were also analysed, looking at the years of nursing and years nursing in ICU to see if these factors impacted on perception of workplace stressors. The complete results are presented in Chapter 5.

The textual data from the focus groups were content analysed. The findings were used to answer certain elements of inquiry that were beyond the capacity of the mNSS. These results are presented in Chapter 6.

3.5.3 Instrument to measure patient and the healthcare system outcomes

Outcomes for the patient and healthcare system were measured as shown in Figure 3.5. The foci were muscle measurements, mortality, ventilator hours, length of stay in the ICU and the hospital stay. The data were collected in a structured and systematic way in a purpose designed instrument that was titled, the family assisted passive exercise instrument (FAPEI). This tool was developed in REDCap and also collected the patient and family demographics and the data from the CCFNI and NMI completed by them (appendix 12). This allowed the data to down loaded into Excel spreadsheets for ease of analysis.

Figure 3. 6: Instrument and timelines for patients and healthcare system

3.5.3.1 Muscle Measurement

The patients were physically assessed during their stay in ICU by the measurement of muscle groups in their arms and legs to determine if the passive exercising prevented muscle wasting. Measurements were taken using ultrasound technology and a tape measure (Berry & Morris 2013; Gruther et al. 2008). As there was no one with the appropriate skill set to take ultrasound measurements, funding was obtained to send both the senior physiotherapist and the CNC to a one day training session to learn how to take ultrasound measurements.

The muscle thickness was measured by using a portable *Sonosite* turbo ultrasound machine, equipped with built in electronic callipers on a frozen real-time cross-sectional image. The measurements were made at sites most accessible and easily identifiable in subjects in supine position. The points of measure were taken as specified clinically (Campbell et al. 1995; Rodriguez et al. 2012), that is, in the anterior upper arm, forearm and anterior thigh. In the

anterior upper arm, it was taken midway from the tip of the acromion and the olecranon. In the forearm, it was taken midway from the antecubital skin crease and ulnar styloid. The anterior thigh was measured at the midway point between the tip of the greater trochanter and the lateral joint line of the knee. To supplement these measurements, a measure of the thickness of the circumference of the limbs was taken using a standard tape measure, at the same time as the ultrasound measurements. The sites were marked for consistency and were conducted by the same examiner for the duration of ICU admission. This replicated a previous study that determined that limiting the clinicians taking the measurements was important to avoid performance bias (Gruther et al. 2008).

Measurements were taken during the course of the patient's admission in ICU and ceased when the patient was transferred out. There was some inconsistency with the timing of these measurements due to availabity of the tester and when the patient was admitted or enrolled into the study, such as weekends. The results were analysed using non-parametric testing, both Mann-Whitney U test and paired Wilcoxon signed-rank test. These results are presented in Chapter 4.

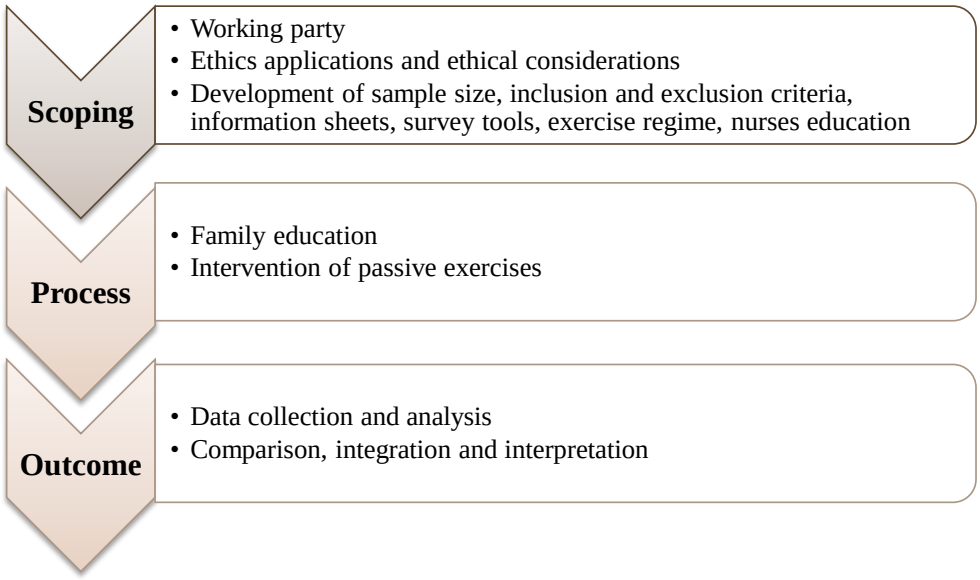
3.5.3.2 Patient and healthcare system outcomes

Other data collected from the ICU EMR in relation to the patient and healthcare system outcomes were the: number of hours the patient received assisted mechanical ventilation; duration of their stay in ICU and the hospital; and, health status (alive or deceased). This was collected on the FAPEI when the patient was discharged from the ICU. Analysis was with the non-parametric Mann-Whitney U test. Patient and family demographics were also collected from the EMR. This included: the patient's age, gender and ethnicity; the gender of their family member; the disease process that had led to their hospital admission; whether they lived in the LHD; and, whether they had been transferred from another hospital or LHD. These results are presented in Chapter 4.

3.6 Study phases

As discussed in Chapter 1, the study design used an SPO model (Donabedian 1988). Figure 3.6, shows the study phases of the study design which are expanded on in this sectio

Figure 3. 7: Study Phases



3.6.1 Scoping

The scoping phase used change management principles that were guided by Kotter's change model (1996) shown in Table 3.7 (Appelbaum et al. 2012; Kotter 1996; Lunenberg 2010). Initially there was a planning phase that included a working party of nurses from both the active and control units, who understood the purpose of the study. This required appropriate collaboration and effective communication and allowing them to be involved with the various stages of the study. For this to occur, a working party of ICU experts that were clinical staff that included the CNC, CNEs, physiotherapist and RNs from both units met weekly in the ICU from January 2015 to the study going live in May 2015.

Table 3. 7: Kotter's eight-step process for implementing change

Step	Description
1. Establish a sense of urgency	Create a compelling reason for why change is needed, as people will not change if they cannot see the need to do so
2. Create the guiding coalition	Create a group of people with enough power to lead the change
3. Develop a vision and strategy	Tell people why the change is needed and how it will be achieved
4. Communicate the change vision	Create and implement a communication strategy that consistently communicates the changes and the aims of the study
5. Empower broad-based action	Eliminate barriers to change by involving people in the change effort. Get people to think about the changes and how to achieve them rather than thinking about why they do not like the changes and how to stop them
6. Generate short-term wins.	Seeing the changes happening and working and recognizing the work being done by people towards achieving the change is critical
7. Consolidate gains and produce more change	The guiding coalition uses credibility from short-term wins to create more change. Additional people are brought into the change process as change cascades throughout the organization. Attempts are made to reinvigorate the change process
8. Anchor new approaches in the culture	To prevent people's tendency to revert to the 'old' way of doing things, it has to become part of the culture

(Appelbaum et al. 2012; Lunenberg 2010)

Once the study went live, the meetings went to fortnightly with the group, but there were daily meetings with the CNC who was the clinical lead and had the clinical oversight. This group provided expertise in ICU patient nursing care and assisted with scoping the study. The RNs responded to an expression of interest to participate in this part of the study and would become the champions in each of the units, in keeping with these principles (Appelbaum et al. 2012; Kotter 1996).

During this period the research objectives and research requirements were discussed and developed. This included the: sample size; inclusion and exclusion criteria for patients and families; exercise regime; information sheets and pamphlets; and, survey tools.

3.6.1.1 Ethics application

In February 2015, an application was made to the hospital and university Human Research Ethics Committee (HREC) submitting the outline of the research, the information sheets, consent forms, surveys and exercise sheets. Approval was given by both the hospital and the university:

RPAH: Protocol: No X15-0059 & HREC/15/RPAH/88

University Tasmania: H0014952 Family assisted passive exercising

In early 2016 after the initial ethics approval was given an amendment to ethics was applied for. The amendment was to conduct the focus groups with the nurses. This amendment was also approved by both sites.

3.6.1.2 Data management and confidentiality

To build trust and to encourage participation in the study confidentiality was assured for both the families and the nurses (Ermakova, Fabian & Zarnekow 2016). This was achieved by distributing the surveys by hand in paper format. Family members then handed the surveys back to the CNC in a sealed envelope. The nurses put their completed forms into sealed boxes in their respective units.

The data from the surveys completed by the families were identified numerically by the Researcher and the ICU CNC, so the demographic data from the EMR could be matched. Once the information was gathered, the records were de-identified to ensure anonymity (Rothstein 2010).

The surveys completed by the nurses were not traceable to individuals. The nursing focus groups were recorded with permission of the participants, after they were informed, consented and assured that the transcripts would not identify them (Kaiser 2009). The focus group recordings were secured on a password protected computer and the transcripts de-identified.

Study data were collected and managed using REDCap electronic data capture tools hosted by the Clinical Research Centre at Sydney Local Health Disctrict. REDCap (Research

Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external source (Harris et al 2009).This data were only accessible to the Researcher and the CNC ICU. All the paper forms, surveys and data collection sheets were stored in a locked cabinet within a secure office. After seven years, all paper records will be destroyed by shredding and the database will be deleted.

3.6.1.3 Information sheets and consent forms

The information and consent forms for the nurses' and family members were developed using templates from the hospital HREC. Table 3.8 provides a list of these information letters and pamphlets and their location in the appendice.

Table 3. 8: List of information letters and pamphlets

Appendix	Information letters and pamphlets	Comment
1	Letter to staff	Informing staff of the study and their part in it
2	Patient screening tool	Used daily to assess patient and family eligibility to participate in the study
3	Information pamphlets for family participants active unit	Explaining the study
4	Information pamphlets for family participants control unit	Explaining the study
5	Family consent form	Giving permission for themselves and the patient to participate in the study
6	Passive range of motion exercises	Passive and resistive range of motion exercises (ALS 2004)
7	Passive limb exercise record	Completed by family in the active unit and the nurses n the control unit
8	Letter to nurses inviting them to participate in focus group	Informing staff of the purpose of the focus groups
9	Nurses' consent form for participation in focus groups	Giving permission to be take part in the focus group

The information pamphlets were developed for the active and the control units (Appendix 3 and 4). These pamphlets explained the purpose of the study and the anticipated benefits; it also explained that participation was voluntary and that there were no foreseeable risks. The process of confidentiality was explained and families were assured that the patient's information would be de-identified. The ethics and complaint process was outlined and

families were advised that there were no financial costs to them and that they would not be receiving any payment.

3.6.2 Process

The process stage was the go-live part of the study with families assisting with passive exercises. This required ensuring that the nurses were informed and educated about the study so that they could teach the families in the active unit and undertake the exercises in the control unit.

3.6.2.1 Passive exercises: and education of nurses and families on how to deliver them

The working party of nurses and physiotherapy staff reviewed and timed the proposed exercise regime prior to the study going live with the families. This trial and discussion was to ascertain how onerous it would be for the nurses and families to conduct the exercises. On average the exercises took approximately six minutes. The working party then assisted with the education and training of the direct care nurses of the active and control units. This was at orientation for new staff and at structured in-service education for existing staff. This was to ensure that staff were comfortable performing the exercises, prior to educating the families. To ensure that there was wide dissemination of information for the nurses: an overview of the study; the pathway to assist in determining the appropriate patients and family for the study; information sheets for families; exercise regimes and survey tools, were all placed on the ICU share drive of each bedside computer for staff reference.

The exercises were conducted on all patients in both the active and control units by the nurses as standard care. If the patients had been enrolled by the family member to be part of the study, then in the control unit, the nurses conducted the exercises. In the active unit the family were given a demonstration on how to do the exercises under the supervision of the direct care nurse. This was to ensure that they knew: what to do, so as to avoid injury to them or the patient; what to avoid, such as intravenous or intra-arterial lines. As the patients in the study were receiving mechanical ventilation, they had a dedicated nurse looking after them. This ensured that the families had supervision when conducting the exercises and an opportunity to ask questions at any time.

The exercises and exercise regime were based on *Passive and resistive range of motion exercises* (ALS 2004) and previous ICU research involving early mobility therapy of acute respiratory failure patients (Morris et al. 2008). The exercises (Morris et al. 2008) involved a passive range of motion (PROM) to the patient's four limbs three times a day for a period of six minutes:

> 'For the upper extremities fingers were flexed and extended; wrists flexed, extended and ulnar and radial deviation; elbow flexion, extension, supination and pronation; shoulder flexion, abduction, and internal and external rotation. For the lower limbs, toes were flexed and extended; ankles dorsiflexion, plantar flexion, inversion and eversion; knee flexion and extension; and hip flexion, abduction, adduction, internal and external rotation' (Morris 2008, p.2239)

The working party developed: a passive exercise pictorial pamphlet, which was given to the family (Appendix 6); and a passive limb exercise record (Appendix 7) that was filled in after the exercises had been completed. This was by the family members in collaboration with the nurses in the active unit and by the direct care nurses in the control unit.

3.6.3 Outcome

The outcome stage of the study was the gathering of the data and the analysis. This process has been presented in Section 3.5 and will be discussed further in Chapters 4, 5 and 6.

3.7 Conclusion

This chapter has presented the research design and the justification for the approach. Limitations of the study design that could impact on generalisability of the findings have been identified and discussed. The setting and the staffing model for the ICU and the sampling and recruitment process for the patient and their families and the nurses have been presented. Additionally, all instruments used to measure the outcomes for the families, patients, nurses and healthcare system have been presented. The rationale for their use and the methods of analysis for each tool has been explained. The chapter concluded by presenting the study phases.

The following three chapters present the data obtained from the instruments. Chapter 4 presents the quantitative results for the families, patients and healthcare system. This includes

the results of the CCFNI completed by the families and nurses, and the NMI and FFS completed by the families. Also presented are the patient and family demographics, muscle measurements, ventilator hours, length of stay in ICU and hospital and mortality. Chapter 5 presents the quantitative results of the mNSS and chapter 6 presents the results of the nurses' focus groups.

Chapter 4 Assessment of the impact on the family, patient and healthcare system

4.1 Introduction

Chapter 3 presented the research design and the instruments that were used to evaluate this study. This chapter is the first of three findings chapters and is structured as follows. First, an overview of the focus of this chapter is presented (section 4.2). This is followed by establishing the participant cohort of the families and patients (section 4.3) and then the demographics of these two groups (section 4.4). The results and analysis of the instruments follow and include: the CCFNI completed by the family and nurses of both the active and control units (section 4.5); the NMI completed by the families of the active and control units (section 4.6); the FSS completed by the families of the active and control units (section 4.7); the clinical outcomes for the patient of the active and control units and the healthcare system are presented in tandem (section 4.8). The chapter concludes summarising the results for the families, patients and the healthcare system (section 4.9)

4.2 Focus upon the family, patient and healthcare system

The focus of this chapter is upon the families, patient and healthcare system, Table 4.1 below gives an overview of the chapter and shows the links between: the research questions for each of these elements; the instruments used to answer the research question; the timeframe for when the instruments were used and the purpose of the analysis.

Table 4. 1: Instruments used to address the research questions

Section	Question	Instrument	Participants	Timeframe	Purpose
4.5	Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for the families?	CCFNI	Families active and control units	Pre-test	To determine perception of needs of family members pre-test
			Nurses active and control units	Pre- and post-test	To determine if nurses' perception of family needs matched those of the respective family members pre-test and to see if the intervention had any impact on findings post-test

Section	Question	Instrument	Participants	Timeframe	Purpose
4.6	Can family assisted passive exercises on unconscious patients in an Intensive Care Unit achieve better outcomes for the family?	NMI	Families active and control units	Post-test	To determine if the perception of needs of family members pre-test were met post-test
4.7	Can family assisted passive exercises on unconscious patients in an Intensive Care Unit achieve better outcomes for the family?	FFS	Families active and control units	Post-test	To measure overall satisfaction of the families
4.8.1	Can family assisted passive exercises on unconscious patients in an Intensive Care Unit achieve better outcomes for the patient?	Muscle measurement using ultrasound and a tape measure	Patient	Post-test	To determine if the passive exercising prevented muscle wasting
4.8.2	Can family assisted passive exercises on unconscious patients in an Intensive Care Unit achieve better outcomes for the patient and healthcare system?	Purpose built study tool-measuring, mortality, ventilator hours, length of stay in ICU and hospital	Patient and healthcare system	Post-test	To determine if the passive exercising reduced ventilator hours, length of ICU and hospital stay and mortality

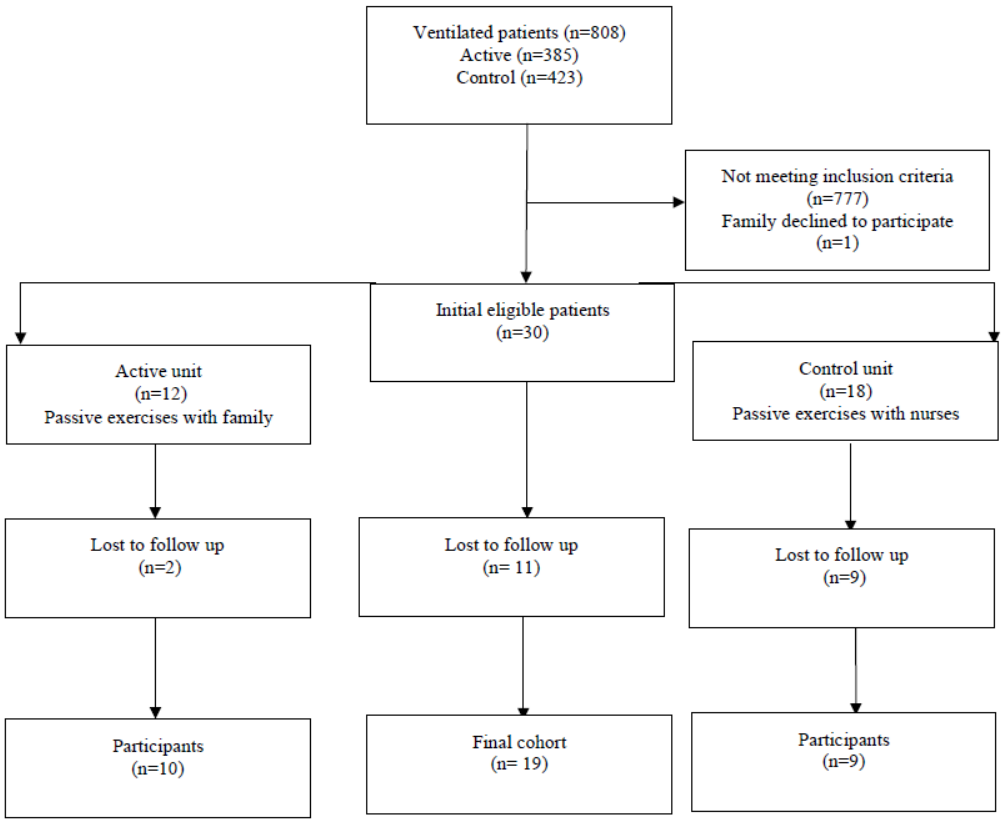
4.3 Establishing the participants cohort

As discussed in Chapter 3, the National Statistical Sampler (Table 3.1), determined, 30 patients and family participants for the study. The aim was to recruit 15 participants in the active unit and 15 participants in the control unit. The recruitment period went from May 2015 to May 2016. As shown in Figure 4.1, during this period 808 ventilated patients were admitted to the study units. The allocation of patients was by the bed managers of the ICU and the hospital and depended on bed availability in the unit, rather than an allocation based on the study. The active unit admitted (n=385; 48%) patients and the control unit (n=423; 52%). These patients were screened daily by a member of the research team and as shown in Figure 4.1, (n=777; 96%) patients were excluded as not meeting the criteria. One family declined to participate.

The 30 patients and their families were recruited; (n=12; 40%) were admitted to the active unit and (n=18; 60%) were admitted to the control unit; of those 30 participants (n=11; 37%) families were lost to follow up; of those 11, (n= 2; 18%) were from the active unit and (n= 9;

82%) were from the control unit. In the active unit both patients lost to follow-up died. Whereas, in the control unit, four of the patients died, one patient was transferred to another facility, one patient was discharged home from ICU and three families did not respond to multiple requests to return the forms. This gave a participation rate of (n=10; 83%) for the active unit and (n=9; 50%) for the control unit. This selection process did not create any bias and even though there were patients and families lost to follow-up it did not change the sample characteristics as demonstrated in the findings below. Patients that were not part of the study received standard care that is the nurses performing the passive exercises.

Figure 4. 1: Flow diagram, establishing the participants' cohort



4.4 Patient and family demographics

This section presents the patient and family demographics of those enrolled, those lost to follow-up and the final cohort of patients and families. This information was gathered as it had not been examined previously and demographic attributes, such as age and gender would confirm whether the two units were comparable (Chen et al. 2015).

The demographics collected included: the age and gender of the patient; the gender of the family member; the ethnicity of the patient; the presenting disease process that the patient was admitted with; whether they were from the LHD and whether they had been referred from another hospital or LHD. Tables 4.2 to 4.8 present these details.

Table 4.2 presents: the median, mean, range and standard deviation of the patients' age for all the enrolled patients in both, the active and control units. This shows that the age distribution was consistent across both units with the overall mean and median age being 55 years. In the active unit the mean age was 49 years and the median age 53 years and in the control unit the mean age was 59 years with a median age of 61 years.

Table 4. 2: Age of all enrolled patients

Demographic	Total (n=30)				Active unit (n=12)				Control unit (n=18)			
	Mean	SD	Range	Med	Mean	SD	Range	Med	Mean	SD	Range	Med
Patient's Age Years	55	16	16-83	55	49	15	16-72	53	59	16	37-83	61

This data were compared to the age of the cohort that was lost to follow-up (Table 4.3) and the age of the patients that completed all parts of the study (Table 4.4). After attrition the age differential between the active and control unit were more aligned, as the variance created by the younger patients that were lost to attrition, equalised the age across both units.

Table 4. 3: Age of patients lost to follow-up

Demographic	Total (n=11)				Active unit (n=2)				Control unit (n=9)			
	Mean	SD	Range	Med	Mean	SD	Range	Med	Mean	SD	Range	Med
Patient's Age Years	53	20	16-77	52	34	25	16-51	34	57	17.8	21-77	59

Table 4. 4: Age of remaining patients

Demographic	Total (n=19)				Active unit (n=10)				Control unit (n=9)			
	Mean	SD	Range	Med	Mean	SD	Range	Med	Mean	SD	Range	Med
Patient's Age Years	56	14	43-83	55	52	12	45-66	53	60	15	43-83	61

Table 4.5 presents the demographic characteristics of the enrolled patients and their families, across the active and control units.

The majority of the patients were male (n=24; 80%). The majority of the family members were female, (n= 28; 93%).

Half of the patients identified as Australian, (n=15; 50%), of these (n= 2; 7%) identified as indigenous Australian.

The majority of the patients were admitted to the ICU either with a respiratory (n=8; 27%) or liver (n=10; 33%) disease process.

Only (n= 8; 27%) of the patients were from the LHD, and (n=13; 43%), were referred from other hospitals around Sydney and NSW for tertiary and quaternary level care.

Table 4. 5: Demographics of all enrolled patients and their families

Demographic	Total n=30 (100%)	Active unit n=12 (100%)	Control unit n=18 (100%)
Male patient	24 (80)	10 (83)	14 (78)
Female family	28 (93)	11 (92)	17 (94)
Ethnicity- **Australian** **(Indigenous)**	 15 (50) 2 (7)	 7 (58) 2 (17)	 8 (44) 0 (0)
Disease- **respiratory** **liver**	 9 (27) 10 (33)	 6 (50) 2 (17)	 3 (17) 8 (4)
From LHD	8 (27)	2 (17)	6 (33)
Referred	13 (43)	6 (50)	7 (39)

The demographics of the patient and family lost to follow-up (Table 4.6) and the remaining participants (Table 4.7) were compared against the original 30 enrolled (Table 4.8). This showed consistency across all the groups.

Table 4. 6: Demographics of those patients and their families lost to follow-up

Demographic	Total n=11 (100%)	Active unit n=2 (100%)	Control unit n=9 (100%)
Male patient	8 (73)	1 (50)	7 (78)
Female family	11 (100)	2 (100)	9 (100)
Ethnicity- **Australian** **(Indigenous)**	 4 (36) 0 (0)	 2 (100) 0 (0)	 2 (22) 0 (0)
Disease- **Respiratory** **Liver**	 4 (36) 4 (36)	 2 (100) 0 (0)	 2 (22) 4 (44)
From LHD	4 (36)	1 (50)	3 (33)
Referred	5 (46)	1 (50)	4 (4)

Table 4. 7: Demographics of the remaining patients and their families

Demographic	Total n=19 (100%)	Active unit n=10 (100%)	Control unit n=9 (100%)
Male patient	16 (84)	9 (90)	7 (78)
Female Family	17 (90)	9 (90)	8 (89)
Ethnicity- **Australian** **(Indigenous)**	 11 (58) 2 (11)	 5 (50) 2 (20)	 6 (67) 0 (0)
Disease- **Respiratory** **Liver**	 5 (26) 6 (32)	 4 (40) 2 (20)	 1 (11) 4 (36)
From LHD	4 (21)	1 (10)	3 (33)
Referred	8 (42)	5 (50)	3 (33)

Table 4. 8: Comparison of all enrolled, those lost to follow-up and final cohort of patients and families

Demographic	Total n=30 (100%)	Lost to follow-up n=11 (100%)	Remaining n=19 (100%)
Male patient	24 (80)	8 (73)	16 (84)
Female Family	28 (93)	11 (100)	17 (90)
Ethnicity- **Australian**	15 (50)	4 (36)	11 (58)
Disease- **Respiratory** **Liver**	 9 (27) 10 (33)	 4 (36) 4 (36)	 5 (26) 6 (32)
From LHD	8(27)	4(36)	4 (21)
Referred	13 (43)	5 (46)	8 (42)

4.5 Results and analysis of the Critical Care Family Needs Inventory

The CCFNI was completed by the family when their family member was admitted to the ICU. It was returned by (n=10; 83 %) families in the active unit and by (n=14; 78 %) in the control unit. Of the families that completed the CCFNI (n=10; 100%) in the active unit and (n=9; 64%) in the control unit completed the NMI. The following CCFNI results include only those from families that completed both the CCFNI and NMI.

The nurses completed the CCFNI pre- and post-test. In the active unit (n=45; 80%) completed the surveys in the pre-test phase and (n=40; 72%) post-test. In the control unit (n=55; 83%) completed the CCFNI pre-test and (n=40; 85%) post-test.

Means were obtained for both the items and domains of the CCNI as discussed in Chapter 3.5.1.1. Data were analysed using descriptive and inferential statistics. The results of the CCFNI from the families and nurses of the active and control units were analysed as shown in Table 4.9.

Table 4. 9: Analysis of the CCFNI

Time frame	Participants	Purpose	Analysis
Pre-test	Families- active unit	To identify what families perceived were their most important needs	Table 4.10 and 4.11 Frequency analysis of the means of the items and domains of the CCFNI
Pre-test	Nurses- active unit	To identify what nurses perceived families thought were their most important needs	Table 4.10 and 4.11 Frequency analysis of the of the items and domains of the CCFNI
Pre-test	Families v. nurses- active unit	To compare family and nurses perception of need	Table 4.10 and 4.11 Comparison of frequency analysis of the items and domains of the CCFNI Significance tested using Mann-Whitney U test
Post-test	Families v. nurses- active unit	To see whether there had been any change in perception of what nurses thought families needed	Table 4.10 and table 4.11 Comparison of frequency analysis of the items and domains of the CCFNI Significance tested using Mann-Whitney U
Pre-and post-test	Nurses- active unit	To see whether there had been any change in perception of what nurses thought families needed	Table 4.14 Means pre-test compared to means post-test. Significance tested using Mann-Whitney U test
Pre-test	Families- control unit	To identify what families perceived as their most important need	Table 4.12 and 4.13 Means of the items and domains of the CCFNI.
Pre-test	Nurses- control unit	To identify what nurses perceived families thought were	Table 4.12 and 4.13 Means of the items and domains of the

Time frame	Participants	Purpose	Analysis
		their most important need	CCFNI.
Pre-test	Families and nurses-control unit	To compare family and nurses perception	Table 4.12 and 4.13 Comparison of means for items and domains of the CCFN Significance tested using Mann-Whitney U test.
Post-test	Families v. nurses-control unit	To see whether there had been any change in perception of what nurses thought families needed	Table 4.12 and 4.13 Comparison of means for items and domains of the CCFNI Significance tested using Mann-Whitney U test.
Pre- and post-test	Nurses-control unit	To see whether there had been any change in perception of what nurses thought families needed	Table 4.15 Means pre-test compared to means post-test Significance tested using Mann-Whitney U test
Pre- and post-test	Nurses-active and control units	To compare the units pre- to post-test to see the perception of family need and whether there was any change in perception of family needs between units	Table 4.16 Analysis by domains pre- to post-test between the units Significance tested using Mann-Whitney U test

4.5.1 Comparison of the CCFNI results between the active unit families pre-test to active unit nurses pre- and post-test

The data were analysed by:

1. Ranking the means of perceived importance.
2. Comparing the means, between the results from the families pre-test to the nurses pre- and post-test.
3. Testing significance using the non-parametric Mann-Whitney U test (Sutkowi 1995; Takman & Severinsson 2005; Williams 1989).

Table 4.10 presents the means and significance ratings of perceived importance of individual needs statement. Table 4.11 presents the means and significance of the five domains. As each domain has discreet parameters (Column A), to determine which one was perceived as the most important by the families and nurses; a percentage value was given to each mean.

Table 4. 10: Means, significance ratings of perceived importance of needs active unit: families pre-test to the nurses' pre- and post- test

			A	B	C	D	E
Rank	**Domain**	**Individual needs item**	**Family (n=10) pre-test mean**	**Nurses (n=45) pre-test mean**	**(Z) *P* family v. nurses pre-test**	**Nurses (n=40) post-test mean**	**(Z) *P* family v. nurses post-test**
1	Assurance	13.To be assured that the best possible care was being given to the patient	4.0	3.7	(-2.02) *.04	3.8	(-1.08) .34
2	Assurance	26. To have questions answered honestly	4.0	3.6	(-2.22) *.03	3.8	(-1.49) .34
3	Assurance	20. To know the prognosis	3.9	3.3	(-1.68) .09	3.7	(-1.07) .47
4	Assurance	22.To feel there was hope	3.9	3.3	(-2.46) *.01	3.6	(-1.34) .17
5	Proximity	10. To see the patient frequently	3.9	3.3	(-2.08) *.01	3.5	(-1.70) .11
6	Proximity	14. To be called at home about changes in the patient's condition	3.9	3.0	(-3.24) *.001	3.1	(-1.12) *.04
7	Proximity	17. To talk with the nurse each day	3.9	3.3	(-2.68) *.01	3.3	(-.49) *.01
8	Proximity	25. To receive information about the patient once a day	3.9	3.3	(-2.68) *.01	3.4	(-1.27) .11
9	Assurance	27. To feel that hospital personnel cared about the patient	3.8	3.5	(-.92) .36	3.7	(-1.34) .88
10	Assurance	29. To know specific facts about the patient's condition	3.8	3.2	(-2.31) *.02	3.6	(-2.35) .45
11	Assurance	30. To have explanations given in terms that are understandable	3.8	3.7	(-.33) .75	3.9	(-1.35) .75
12	Information	7. To know why things were being done for the patient	3.8	3.6	(-1.08) .28	3.7	(-.96) .71
13	Information	8. To know what exactly was being done for the patient	3.8	3.4	(-1.93) .05	3.6	(-1.71) .51
14	Proximity	11. To be told about transfer plans when they were being made	3.8	3.5	(-1.26) .21	3.6	(-1.11) .68
15	Proximity	24. To have visiting hours changed for special conditions	3.8	3.3	(-2.08) *.04	3.6	(-1.67) .37
16	Support	18. To talk about the possibility of the patient's death	3.7	3.2	(-1.78) .08	3.1	(-1.34) *.05
17	Information	3. To know how the patient is being treated	3.7	3.7	(-.21) .83	3.8	(-.46) .66
18	Information	2. To talk to the doctor every day	3.6	3.5	(-.93) .35	3.6	(-.98) .75
19	Support	9. To have someone concerned with the family member's health	3.5	3.3	(-1.51) .13	3.4	(-.94) .42
20	Proximity	16. To help with the patient's physical care	3.5	2.7	(-2.50) *.01	3.0	(-1.42) .08
21	Comfort	1.To feel accepted by the hospital staff	3.4	3.3	(-.28) .78	3.3	(-.07) .84
22	Information	12.To know about the types of staff taking care of the patient	3.4	2.8	(-1.89) .06	2.8	(-.01) *.05
23	Information	23.To have a specific person to call at the hospital when not there	3.4	2.7	(-2.19) *.03	3.0	(-1.48) .21
24	Support	5.To have directions of what to do at the bedside	3.2	3.1	(-.23) .82	3.2	(-.29) .97
25	Support	21.Explanation of the environment	3.1	3.1	(-.06) .95	3.2	(-.94) .62
26	Support	28.To be told about other people that could help with problems	3.1	3.2	(-.11) .91	3.4	(-1.51) .40
27	Proximity	6.To have visiting times start on time	3.1	3.0	(-.06) .95	3.3	(-1.27) .53
28	Support	15.To have friends nearby for support	3.0	3.0	(-.37) .71	3.1	(-.67) .97
29	Proximity	4.To talk about feelings	2.3	3.0	(-2.06) *.04	3.1	(-.52) *.04
30	Comfort	19.To have a telephone in the waiting room	2.2	2.6	(-1.25) .21	2.8	(-.82) .13

*Significant at *P=≤ .05* Mann-Whitney U test

Table 4. 11: Means and significance ratings of the domains: active unit families pre-test compared to active unit nurses pre- and post- test

	A	B	C	D	E	F
Domain	**Score**	**Family (n=10) pre-test mean %**	**Nurses (n=45) pre-test mean %**	**(Z) *P* family v. nurses pre-test**	**Nurses (n=40) post-test mean %**	**(Z) *P* family pre-test v. nurses post-test**
1.Support	24	21.9 (91)	21.9 (91)	(-.31) .76	22.5 (94)	(-1.03) .73
2.Comfort	8	5.6 (70)	5.9 (74)	(-60) .55	6.1 (76)	(.78) .33
3.Assurance	28	27.2 (97)	24.3 (87)	(-2.79) *.01	26.1 (93)	(2.34) .27
4.Information	24	21.7 (90)	19.7 (82)	(-2.31) *.02	20.5 (85)	(-1.51) .10
5.Proximity	36	29.8 (83)	25.4 (71)	(-3.18) *.001	26.8 (74)	(-1.80) *.01

* *Significant at P=≤*.05 Mann-Whitney U test

4.5.1.1 Active unit pre-test

The results as presented in Table 4.10 show that, pre-test the families ranked four items from the assurance domain their highest needs. These included: *to be assured that the best possible care was being given to the patient; to have questions answered honestly; to know the prognosis* and *to feel there was hope.* The family also ranked highly (from the proximity domain): *to see the patient frequently; to be called at home about changes in the patient's condition; to talk to the nurse each day* and *to receive information about the patient once a day.*

The nurses ranked all the items lower than the families. The top mean score for the families were 4.0, whereas the top score for the nurses was 3.7. The top three ranked items from the nurses' perception aligned with the family and were*: to be assured that the best possible of care was being given to the patient; to have explanations given in terms that are understandable* from the assurance domain and *to know how the patient is being treated* from the information domain.

There were 12 items and three domains that showed statistically significant differences (*P*=≤.05) between the families' and nurses' groups. The items of difference were: *to be assured that the best possible care was being given to the patient; to have questions answered honestly; to feel there was hope; to see the patient frequently; to be called at home about changes in the patient's condition; to talk with the nurse each day; to receive*

information about the patient once a day; to know specific facts about the patient's condition; to have visiting hours changed for special conditions; to help with the patient's physical care; to have a specific person to call at the hospital when not there and *to talk about feelings.* These needs were from the domains of assurance, information and proximity and demonstrated that the nurses and the families' perceptions on these needs were not aligned.

The comparison of the domains (Table 4 .11), demonstrates that the family ranked the assurance domain the highest (97%). Pre-test the nurses did not rank this domain as high (87%) showing significance (*P*=*.01).

4.5.1.2 Active unit post-test

Post-test for the nurses the means of 26 items increased, three remained the same and one item deteriorated. Three items now showed statistically significant differences (*P*=≤.05) showing that there was still a disparity between the families' and nurses' perception on these needs. All were from the proximity domain including: *to be called at home about changes in the patient's condition; to talk with the nurse each day* (ranked higher by the families) and *to talk about feelings* (ranked higher by the nurses).

Two items showed a marginally significant difference *(P*= .05) including: *to talk about the possibility of the patient's death* from the support domain; and *to know the type of staff taking care of the patient* from the information domain. Both items were ranked lower by the nurses.

The means of all the domains showed a positive improvement with a statistical improvement (*P*=.01) in the proximity domain. This demonstrated that post-test the perception of families' needs between the families and the nurses were more aligned.

4.5.2 Comparison of the CCFNI results between the control unit families pre-test to control unit nurses pre- and post-test

The data were analysed by:

1. Ranking the means of perceived importance.
2. Comparing the means, between the results from the families pre-test to the nurses pre- and post-test.

3. Testing significance using the non-parametric Mann-Whitney U test (Sutkowi 1995; Takman & Severinsson 2005; Williams 1989).

Table 4.12 presents the means and significance ratings of perceived importance of individual needs statement. Table 4.13 presents the means and significance of the five domains. As with the active unit, a percentage value was given to each mean (column A).

Table 4. 12: Means, significance ratings of perceived importance of needs control unit: families pre-test to the nurses' pre- and post- test

			A	B	C	D	E
Rank	**Domain**	**Individual needs item**	**Family (n=9) pre-test mean**	**Nurses (n=55) pre-test mean**	**(Z) *P* family v. nurses pre-test**	**Nurses (n=40) post-test mean**	**(Z) *P* family v. nurses post-test**
1	Assurance	26. To have questions answered honestly	3.9	3.7	(-1.05) .29	3.7	(-.17).39
2	Assurance	30. To have explanations given in terms that are understandable	3.9	3.7	(-.86) .39	3.7	(-1.31).22
3	Assurance	20. To know the prognosis	3.9	3.6	(-1.09) .28	3.5	(-1.43).14
4	Information	8. To know what exactly was being done for the patient	3.9	3.5	(-1.95) *.05	3.4	(-1.42).26
5	Proximity	25. To receive information about the patient once a day	3.9	3.4	(-1.34) .18	3.3	(-.09)*.02
6	Assurance	29. To know specific facts about the patient's condition	3.9	3.3	(-2.65) *.01	3.4	(-.09).26
7	Assurance	13. To be assured that the best possible care was being given to patient	3.8	3.7	(-1.44) .89	3.8	(-.05).93
8	Assurance	27. To feel that hospital personnel cared about the patient	3.8	3.7	(-.53) .56	3.7	(-.31).77
9	Information	3. To know how the patient is being treated	3.8	3.8	(-.72) .47	3.7	(-2.03).71
10	Information	7. To know why things were being done for the patient	3.8	3.7	(-.57) .57	3.6	(-.53).48
11	Proximity	10. To see the patient frequently	3.8	3.4	(-1.64) .10	3.4	(-.24).12
12	Proximity	14. To be called at home about changes in the patient's condition	3.8	3.2	(-1.92) *.01	3.3	(-.21).08
13	Proximity	17. To talk with the nurse each day	3.8	3.3	(-2.07) *.04	3.5	(-1.17).15
14	Support	18. To talk about the possibility of the patient's death	3.7	3.2	(-1.79) .07	3.2	(-.25).13
15	Support	28 .To be told about other people that could help with problems	3.7	3.3	(-1.34) .18	3.3	(-.37).15
16	Assurance	22. To feel there was hope	3.7	3.5	(-.67) .51	3.3	(-1.76).11
17	Proximity	11. To be told about transfer plans when they were being made	3.7	3.5	(.51) .61	3.4	(-1.04).33
18	Support	9. To have someone concerned with the family member's health	3.6	3.3	(-.59) .56	3.4	(-.22).50
19	Comfort	1. To feel accepted by the hospital staff	3.6	3.6	(-.32) .75	3.5	(-.01).79
20	Information	2. To talk to the doctor each day	3.4	3.6	(-.88) .38	3.6	(-1.07).81
21	Information	12. To know about the types of staff taking care of the patient	3.4	2.9	(-1.78) .08	2.9	(-.65).21
22	Proximity	6. To have visiting times start on time	3.4	3.3	(-.47) .64	3.2	(-.45).52
23	Proximity	16.To help with the patient's physical care	3.4	2.9	(-1.85) .07	3.1	(-1.08).19
24	Proximity	24.To have visiting hours changed for special needs	3.4	3.5	(-.09) .93	3.3	(-1.36).47
25	Support	21.Explanation of the environment	3.3	3.2	(-.28) .82	3.1	(-.88).42
26	Support	5. To have directions what to do at the bedside	3.3	3.1	(-.72) .48	3.2	(-.65).77
27	Information	23.To have a specific person to call at the hospital	3.2	3.1	(-.31) .76	3.2	(-.18).83
28	Support	15.To have friends nearby for support	3.1	3.2	(-.02) .98	3.2	(-.06).97
29	Proximity	4. To talk about feelings	3.0	3.1	(-.06) .95	3.1	(-.11).99
30	Comfort	19.To have a telephone in the waiting room	2.4	2.7	(-.41) .41	2.5	(-1.34).85

*Significant at $P \leq .05$ Mann Whitney U test

Table 4. 13: Means and significance of the domains: control unit families pre-test compared to control unit nurses pre- and post- test

	A	B	C	D	E	F
Domain	**Maximum score**	**Family (n=9) pre-test mean %**	**Nurses (n=55) pre-test mean %**	**(Z) *P* family v. nurses pre-test**	**Nurses (n=40) post-test mean %**	***(Z) P* family v. nurses post-test**
1.Support	24	23.7 (99)	22.4 (93)	(-.81) .42	22.5 (94)	(-.16) .37
2. Comfort	8	6.0 (75)	6.3 (79)	(-.60) .55	6.0 (75)	(-1.07) .91
3. Assurance	28	27.0 (96)	25.2 (90)	(-1.39) .16	24.9 (89)	(-1.29) *.04
4. Information	24	21.5 (90)	20.6 (86)	(-.97) .33	20.8 (87)	(-.04) .35
5. Proximity	36	29.2 (81)	26.5 (74)	(-2.09) *.04	26.6 (74)	(-.17) *.05

*Significant at $P \leq .05$ Mann-Whitney U test

4.5.2.1 Control unit pre-test

Pre-test the families ranked six items from the assurance domain the highest needs. This included: *to have questions answered honestly; to have explanations given in terms that are understandable; to know the prognosis; to know specific facts about the patient's condition; to be assured that the best possible care was being given to the patient* and *to feel that hospital personnel cared about the patient.*

The highest ranked item for the nurses was: *to know how the patient is being treated.* Five other items that were ranked equally in the top needs were; *to have questions answered honestly; to have explanations given in terms that are understandable; to be assured that the best possible care was being given to the patient; to feel that the hospital personnel cared about the patient* and *to know why things were being done for the patient.* The nurses and the families' perceptions on these needs were aligned.

There were three items and the proximity domain that showed statistically significant differences between the family and nurses' groups ($P = \leq .05$). The items were: *to be called at home about changes in the patient's condition* and *to talk with the nurse each day* from the proximity domain and *to know specific facts about the patient's condition* from the assurance domain. The item *to know what exactly was being done for the patient* from the information

domain showed marginal significance. The nurses and the families' perceptions on these needs were not aligned.

The comparison of the domains (Table 4 .13), demonstrated that the family scored the support domain the highest (99%). This was the highest scored domain for the nurses also (93%).

4.5.2.2 Control unit post-test

Post-test for the nurses the means of eight items increased, ten remained the same and 12 items decreased. One item that worsened, from the proximity domain showed a statistically significant difference (*P*=.02): *to receive information about the patient once a day.*

The other 11 items that decreased post-study, two were from the assurance domain, three were from the information domain, three from the proximity domain, two from the comfort domain and one from the support domain. They included: *to know the prognosis; to feel accepted by hospital staff; to know how the patient is being treated; to have visiting times start on time; to know why things were being done for the patient; to know exactly what was being done for the patient; to be told about transfer plans when they were being made; to have a telephone in the waiting room; to know the prognosis; explanation of the environment; to feel there was hope* and *to have visiting hours changed for special needs.*
.

The comparison of the domains post-test (Table 4 .13), showed that the family still scored the support domain the highest (99%). This was the highest scored domain pre- (93%) and post-test (94%) for the nurses. The family also scored the assurance domain high (96%); pre-test for the nurses the score was (90%), post-test the score decreased (89%) and compared to the family showed significance (*P*=.04). Pre- and post-test the nurses did not score the proximity domain as high as the family showing significance. The means of the comfort and assurance domains decreased post-test. There was marginal improvement in the proximity domain. The results showed that there was disparity between the families and the nurses in relation to perceptions of family needs pre- and post-test.

4.5.3 Comparison of the CCFNI results between the nurses of the active and control units pre- and post-test

4.5.3.1 Active unit

Table 4.14 presents the pre- and post-test results of the CCFNI completed by the active unit nurses. The results were compared by the means of the individual needs statements and domains. Testing of significance used non-parametric Mann-Whitney U test (Sutkowi 1995; Takman & Severinsson 2005; Williams 1989).

Post-test the means of, 26 items increased, three items remained the same and only one item; *to talk about the possibility of the patient's death,* from the support domain decreased. One item from the assurance domain showed a statistically significant improvement *(P*=.02) *to know specific facts about the patient's condition.* The means of all the domains increased post-test and there was statistical significance in the assurance domain (*P*=.02).

Table 4. 14: Means and significance of individual items and domains of CCFNI comparison pre- and post-test for nurses of the active unit

Needs by Domains	Nurses (n=45) pre-test mean	Nurses (n=40) post-test mean	(Z) *P*
Support			
4. To talk about feelings	3.0	3.1	(-.52) .60
5. To have directions what to do at the bedside	3.1	3.2	(-.29) .77
9.To have someone concerned with family members health	3.3	3.4	(-.94) .35
15.To have friends nearby for support	3.0	3.1	(-.67) .51
18.To talk about the possibility of the patient's death	3.2	3.1	(-.46) .65
21.Explanation of the environment	3.1	3.2	(-.94) .35
28.To be told about other people that could help with problems	3.2	3.4	(-1.51) .13
Support Domain Score	**21.9**	**22.5**	**(-1.03) .31**
Comfort			
1. To feel accepted by the hospital staff	3.3	3.3	(-.07) .95
19. To have a telephone in the waiting room	2.6	2.8	(.82) .41
Comfort Domain Score	**5.9**	**6.1**	**(-.78) .43**
Assurance			
13.To be assured that the best possible care was being given to the patient	3.7	3.8	(-1.08) .28
20. To know the prognosis	3.3	3.7	(-1.07) .29
22. To feel there was hope	3.3	3.6	(-1.34) .18
26. To have questions answered honestly	3.6	3.8	(-1.49).14
27. To feel that hospital personnel cared about the patient	3.5	3.7	(-1.13) .26
29. To know specific facts about the patient's condition	3.2	3.6	(-2.35)*.02
30. To have explanations given in terms that are understandable	3.7	3.9	(-1.35) .18
Assurance Domain Score	**24.3**	**26.1**	**(-2.34)*.02**
Information			
2.To talk to the doctor every day	3.5	3.6	(-.98) .33
3.To know how the patient is being treated	3.7	3.8	(-.65) .52
7. To know why things were being done for the patient	3.6	3.7	(-.96) .34
8. To know exactly what was being done for the patient	3.4	3.6	(-1.71) .09
12. To know about the types of staff taking care of the patient	2.8	2.8	(-.01) .99
23. To have a specific person to call at the hospital when not there	2.7	3.0	(-1.48) .14
Information Domain Score	**19.7**	**20.5**	**(-1.51) .13**
Proximity			
6. To have visiting times start on time	3.0	3.3	(-1.27) .21
10.To see the patient frequently	3.3	3.5	(-1.70) .09
11. To be told about transfer plans when they were being made	3.5	3.6	(-1.11) .27
14. To be called at home about changes in the patient's condition	3.0	3.1	(-1.12) .26
16. To help with the patient's physical care	2.7	3.0	(-1.42) .16
17. To talk with the nurse each day	3.3	3.3	(-.49) .63
24. To have visiting hours changed for special conditions	3.3	3.6	(-1.67) .10
25. To receive information about the patient once a day	3.3	3.4	(-1.27) .20
Proximity Domain Score	**25.4**	**26.8**	**(-1.80) .07**

*Significant at $P \leq .05$ Mann-Whitney U test

4.5.3.2 Control unit

Table 4.15 presents the pre- and post-test results of the CCFNI completed by the contol unit nurses. The results were compared by the means of the individual needs statements and

domains. Testing of significance used non-parametric Mann-Whitney U test (Sutkowi 1995; Takman & Severinsson 2005; Williams 1989).

Table 4. 15: Means and significance ratings of perceived importance of families' needs comparison pre- and post-study period for nurses of the control unit

Needs by Domains	Pre-test (n=55) mean	Post-test (n=40) mean	(Z) *P*
Support			
4. To talk about feelings	3.1	3.1	(-.11) .91
5. To have directions what to do at the bedside	3.1	3.2	(-.65) .52
9.To have someone concerned with family members health	3.3	3.4	(-.22) .82
15.To have friends nearby for support	3.2	3.2	(-.06) .96
18.To talk about the possibility of the patient's death	3.2	3.2	(-.25) .80
21.Explanation of the environment	3.2	3.1	(-.88) .38
28.To be told about other people that could help with problems	3.3	3.3	(-.37) .71
Support Domain Score	**22.4**	**22.5**	**(-.16) .88**
Comfort			
1. To feel accepted by the hospital staff	3.6	3.5	(-.01) .99
19. To have a telephone in the waiting room	2.7	2.5	(-1.34) .18
Comfort Domain Score	**6.3**	**6.0**	**(-1.07) .29**
Assurance			
13. To be assured that the best possible care was being given to the patient	3.7	3.8	(-.05) .62
20. To know the prognosis	3.6	3.5	(-1.43) .15
22. To feel there was hope	3.5	3.3	(-1.76) .08
26. To have questions answered honestly	3.7	3.7	(-.17) .86
27. To feel that hospital personnel cared about the patient	3.7	3.7	(-.31) .76
29. To know specific facts about the patient's condition	3.3	3.3	(-.09) .93
30. To have explanations given in terms that are understandable	3.7	3.6	(-1.31).19
Assurance Domain Score	**25.2**	**24.9**	**(-1.29) .20**
Information			
2.To talk to the doctor every day	3.6	3.6	(-1.07) .29
3.To know how the patient is being treated	3.8	3.7	(-2.03)*.04
7. To know why things were being done for the patient	3.7	3.6	(-.53) .60
8. To know exactly what was being done for the patient	3.5	3.7	(-1.42).16
12. To know about the types of staff taking care of the patient	2.9	3.0	(-.65) .50
23. To have a specific person to call at the hospital when not there	3.1	3.2	(-.18) .86
Information Domain Score	**20.6**	**20.8**	**(-.04) .97**
Proximity			
6. To have visiting times start on time	3.3	3.2	(-.45).65
10. To see the patient frequently	3.4	3.4	(-.24).81
11. To be told about transfer plans when they were being made	3.5	3.4	(-1.04) .30
14. To be called at home about changes in the patient's condition	3.2	3.3	(-.21).83
16. To help with the patient's physical care	2.9	3.1	(-1.08) .28
17. To talk with the nurse each day	3.3	3.5	(-1.17) .24
24. To have visiting hours changed for special conditions	3.5	3.3	(-1.36) .17
25. To receive information about the patient once a day	3.4	3.4	(-.09) .93
Proximity Domain Score	**26.5**	**26.6**	**(.17) .86**

*Significant at $P \leq .05$ Mann-Whitney U test

Post-test the means of, eight items increased, 10 items remained the same and 12 items decreased. One item from the information domain, showed statistical significance *to know how the patient is being treated* (*P*=.04).There was marginal improvement in the support, information and proximity domains; the assurance and comfort domains decreased post-test.

4.5.4 Comparison of the CCFNI results between the nurses of the active and control units pre- to post-test

The analysis of the domains using the Mann-Whitney U test (Sutkowi, 1995; Takman & Severinsson 2005; Williams 1989;) are presented in Table 4.16, The results show that pre-test there was no significance between the two groups, post-test, the results showed greater improvement in the active unit of the perception of family needs, with significance for the assurance domain (*P*= .01). This confirmed the previous findings that there was greater improvement in perception of family needs in the active unit.

Table 4. 16: Comparison of the CCFNI between the active and control unit nurses pre- to post-test

Domain	Pre-test active unit (n=45)	Pre-test control unit (n=55)	Pre active v. control (Z) *P*	Pre-test active unit (n=40)	Post-test control unit (n=50)	Post active v. control (Z) *P*
1.Support	21.9	22.4	(-.74) .46	22.5	22.5	(-.37) .71
2. Comfort	5.9	6.3	(-1.04) .30	6.1	6.0	(-.74) .46
3. Assurance	24.3	25.2	(-.92) .36	26.1	24.9	(-2.73) *.01
4. Information	19.7	20.6	(-1.84) .07	20.5	20.8	(-.23) .82
5. Proximity	25.4	26.5	(-1.38) .17	26.8	26.6	(-.68) .5

*Significant at $P \leq .05$ Mann-Whitney U test

4.5.5 Summary of the analysis and results of the CCFNI

The results of the CCFNI for the active and control unit families and nurses are summarised in Table 4.17.

Table 4. 17: Summary of the analysis and results of the CCFNI

Time frame	Participants	Purpose	Analysis	Result
Pre-test	Families- active unit	To identify what families perceived were their most important needs	Table 4.10 and 4.11 Comparison of means for items and domains of the CCFNI.	The families ranked four items from the assurance domain and four items from the proximity domain their highest need
Pre- test	Nurses- active unit	To identify what nurses perceived families thought were their most important needs	Table 4.10 and 4.11 Comparison of means for items and domains of the CCFNI.	The nurses scored the means lower, and out of the top eight items that family ranked as their top needs, were aligned on only two items, from the assurance domain
Pre- test	Families and nurses- active unit	To compare family and nurses perception of family need	Table 4.10 and 4.11 Comparison of means for items and domains of the CCFNI, significance tested using Mann-Whitney U test	12 items and three domains showed statistical difference of perception between the families and nurses. There were three items and the proximity domain that showed statistically significant differences ($P = \leq .05$
Post-test	Families and nurses- active unit	To see whether there had been any change in perception of what nurses thought families needed	Table 4.10 and table 4.11 Comparison of means for items and domains of the CCFNI, significance tested using Mann-Whitney U test	The means of 26 items increased, three remained the same and one decreased. All domains increased showing that the families and nurses were more aligned post-test
Pre- and post-test	Nurses- active unit	To see whether there had been any change in perception of what nurses thought families needed	Table 4.14 Comparison of nurses' means pre- to post-test Analysis used non-parametric testing; Mann-Whitney U test	The means of 26 items increased, three remained the same and one decreased (to talk about the possibility of the patient's death). All domains increased and there was statistical significance in the assurance domain (P= .02). showing improved perception of family need from the nurses in the Active Unit
Pre-test	Families- control unit	To identify what families perceived as their most important needs	Table 4.12 and 4.13 Comparison of means for items and domains of the CCFNI	6 of the 8 highest ranked items were from the assurance domain
Pre-test	Nurses- control unit	To identify what nurses perceived families thought were their most important needs	Table 4.12 and 4.13 Comparison of means for items and domains of the CCFNI	The nurses ranked 4 of the top 8 items ranked by the families the same, all were from the assurance domain.
Pre-test	Families and nurses- control unit	To compare family and nurses perception of family need	Table 4.12 and 4.13 Comparison of means for items and domains of the CCFNI; and significance tested using Mann-	Three items and the proximity domain showed statistically significant differences 1 item showed marginal

Time frame	Participants	Purpose	Analysis	Result
			Whitney U test	significance
Post-test	Families and nurses-control unit	To see whether there had been any change in perception of what nurses thought families needed	Table 4.12 and 4.13 Comparison of means for items and domains of the CCFNI; and significance tested using Mann-Whitney U test	Eight items increased, 10 remained the same and 12 items decreased. Only 1 item showed statistical significance (to receive information about the patient once a day)
Pre- and post-test	Nurses-control unit	To see whether there had been any change in perception of what nurses thought families needed	Table 4.15 Comparison of nurses' means pre- to post-test analysis used non-parametric testing Mann-Whitney U test	Eight items increased, 10 remained the same and 12 items decreased. Only 1 item showed statistical significance (to receive information about the patient once a day). The support, information and proximity domains increased marginally. The assurance and comfort domain decreased post study
Pre- and post-test	Nurses-active and control units	To compare the units pre- to post-test to see the perception of family need and whether there was any change in perception of family needs between units	Table 4.16 Analysis by domains pre- to post-test between the units Analysis used non-parametric testing; Mann-Whitney U test	Pre-test there was no significance between the two groups, post-test, the results showed greater improvement in the Active Unit of the perception of family needs, with significance for the assurance domain (P= .01)

4.6 Results and analysis of the Needs Met Inventory

The results of the NMI from the ten families in the active unit and the nine families in the control unit were compared to the results of CCFNI completed by the family on admission of the patient to ICU. This comparison was to determine how well family members perceived that their needs had been met. Analysis was with the paired Wilcoxon signed-rank test.

Table 4. 18: Analysis of the NMI

Time frame	Participants	Purpose	Analysis
Post- study	Families-active unit	To examine whether families perceived that their needs as identified on the CCFNI, were met as identified by the NMI	Table 4.17 and 4.18 Comparison of means for items and domains of the CCFNI, using paired Wilcoxon signed-rank test
Post- study	Families-control unit	To examine whether families perceived that their needs as identified on the CCFNI, were met as identified by the NMI	Table 4.19 and 4.20 Comparison of means for items and domains of the CCFNI using paired Wilcoxon signed-rank test

4.6.1. Active unit

The results of the NMI completed by the families of the active unit are presented in conjunction with the CCFNI, showing the means and significance ratings by individual items in Table 4.19 and by domains in Table 4.20 which included a percentage value given to each mean.

Table 4. 19: CCFNI and NMI paired analysis of means significance ratings for families of the active unit

Rank CCFNI	Domain	Need	A	Rank NMI	B	C
			CCFNI (n=9) mean		NMI (n=9) mean	(Z) *P*
1	Assurance	13.To be assured that the best possible care was being given to the patient	4.0	2	3.8	(-1.41) .16
2	Assurance	26.To have questions answered honestly	4.0	2	3.8	(-1.41) .16
3	Assurance	20.To know the prognosis	3.9	8	3.3	(-2.12) *.03
4	Assurance	22.To feel there was hope	3.9	5	3.5	(-1.41) .17
5	Proximity	10.To see the patient frequently	3.9	2	3.8	(-.58) .56
6	Proximity	14.To be called at home about changes in the patient's condition	3.9	9	3.2	(-1.84) .07
7	Proximity	17.To talk with the nurse each day	3.9	1	4.0	(-1.00) .32
8	Proximity	25.To receive information about the patient once a day	3.9	4	3.6	(-1.73) .08
9	Assurance	27.To feel that hospital personnel cared about the patient	3.8	4	3.6	(-1.41) .16
10	Assurance	29.To know specific facts about the patient's condition	3.8	7	3.4	(-1.41) .16
11	Assurance	30.To have explanations given in terms that are understandable	3.8	5	3.5	(-1.34) .18
12	Information	7.To know why things were being done for the patient	3.8	5	3.5	(-1.00) .32
13	Information	8.To know what exactly was being done for the patient	3.8	5	3.5	(-1.73) .08
14	Proximity	11.To be told about transfer plans when they were being made	3.8	4	3.6	(-1.41) .16
15	Proximity	24.To have visiting hours changed for special conditions	3.8	4	3.6	(-1.00) .32
16	Support	18.To talk about the possibility of the patient's death	3.7	11	2.9	(-1.84) *.05
17	Information	3.To know how the patient is being treated	3.7	5	3.5	(-1.41) .16
18	Information	2.To talk to the doctor every day	3.6	6	3.4	(-.71) .48
19	Support	9.To have someone concerned with the family member's health	3.5	4	3.6	(.00) 1.0
20	Proximity	16.To help with the patient's physical care	3.5	5	3.5	(-.14) .89
21	Comfort	1.To feel accepted by the hospital staff	3.4	4	3.6	(-.71) .48
22	Information	12.To know about the types of staff taking care of the patient	3.4	9	3.2	(-.63) .53
23	Information	23.To have a specific person to call at the hospital when not there	3.4	7	3.4	(.00) 1.0
24	Support	5.To have directions of what to do at the bedside	3.2	3	3.7	(-1.89) *.05
25	Support	21.Explanation of the environment	3.1	8	3.3	(-1.09) .28
26	Support	28.To be told about other people that could help with problems	3.1	11	2.9	(-.92) .36
27	Proximity	6.To have visiting times start on time	3.1	8	3.3	(-.43) .67
28	Support	15.To have friends nearby for support	3.0	8	3.3	(-1.34) .18
29	Proximity	4. To talk about feelings	2.3	10	3.1	(-2.33) *.02
30	Comfort	19.To have a telephone in the waiting room	2.2	11	2.9	(-1.49) .14

**Significant at P=<* .05 Paired Wilcoxon signed-rank test

Table 4. 20: CCFNI and NMI paired analysis of means and significance by domains for families of the active unit

Domain	Score	CCFNI n=10(%)	NMI n=10 (%)	(Z) *P*
1. Support	24	21.9 (91)	22.7 (95)	(-.14) .58
2. Comfort	8	5.6(70)	6.5 (81)	(-1.21) .17
3. Assurance	28	27.2 (97)	24.9 (89)	(-1.95) *.05
4. Information	24	21.7 (90)	20.5 (85)	(-.83) .35
5. Proximity	36	29.8 (83)	28.6 (79)	(-78) .42

**Significant at P=<* .05 Paired Wilcoxon signed-rank test

Six of the top 10 needs identified by the families on the CCFNI were ranked in the top 10 most frequently met as measured by the NMI. The items were all from either the assurance or proximity domains. Two items that were ranked low on the CCFNI showed an increase on the NMI: *to talk about feelings* showed statistical significance (*P*= 0.02) and *to have directions of what to do at the bedside* showed marginal significance (*P*= .05).

Two items that were ranked high on the CCFNI decreased on the NMI and showed significance. They were the third highest need on the CCFNI, *to know the prognosis* (*P*= .02) that now ranked 20th on the NMI and *to talk about the possibility of the patient's death* (*P*= .05) that now ranked 28th. Other items that ranked lower on the NMI were: *to feel there was hope* and *to be called at home about a change in the patient's condition.*

The comparison by the domains (Table 4 .20), showed there was increase in the means of the domains of support (91% to 95%) and comfort (70% to 81%); however the means of the domains of assurance (97% to 89%); information (90% to 85%) and proximity (83% to 79%) decreased post-test.

4.6.2. Control unit

The results of the NMI completed by the families of the control unit are presented in conjunction with the CCFNI, showing the means and significance ratings by individual items in Table 4.21 and by domains in Table 4.22.

Five of the top 10 needs identified by the families on the CCFNI were ranked in the top 10 most frequently met as measured by the NMI.

Four items were from the assurance domain and one from the information domain. They included: *to have questions answered honestly; to have explanations given in terms that are understandable; to know exactly what was being done for the patient; to be assured that the best possible care was being given to the patient* and *to feel that hospital personnel cared about the patient.*

Table 4. 21: CCFNI and NMI paired analysis of means and significance ratings for families of the control unit

Rank CCFNI	Domain	Need	A	Rank NMI	B	C
			Family (n=9) CCFNI mean		Family (n=9) NMI Mean	(Z) *P*
1	Assurance	26.To have questions answered honestly	3.9	1	3.8	(-1.00) .32
2	Assurance	30.To have explanations given in terms that are understandable	3.9	6	3.6	(-1.73) .08
3	Assurance	20.To know the prognosis	3.9	17	3.2	(-1.84) .07
4	Information	8.To know what exactly was being done for the patient	3.9	6	3.6	(-1.34) .18
5	Proximity	25.To receive information about the patient once a day	3.9	10	3.4	(-1.30) .19
6	Assurance	29.To know specific facts about the patient's condition	3.9	10	3.4	(-1.89) .06
7	Assurance	13.To be assured that the best possible care was being given to the patient	3.8	6	3.6	(-1.41) .16
8	Assurance	27.To feel that hospital personnel cared about the patient	3.8	6	3.6	(.00) 1.0
9	Information	3.To know how the patient is being treated	3.8	10	3.4	(-1.60) .11
10	Information	7.To know why things were being done for the patient	3.8	10	3.4	(-1.13) .29
11	Proximity	10.To see the patient frequently	3.8	1	3.8	(.00) 1.0
12	Proximity	14.To be called at home about changes in the patient's condition	3.8	26	2.8	(-2.22) *.03
13	Proximity	17.To talk with the nurse each day	3.8	1	3.8	(.00) 1.0
14	Support	18.To talk about the possibility of the patient's death	3.7	17	3.2	(-1.81) .07
15	Support	28.To be told about other people that could help with problems	3.7	26	2.8	(-2.39) *.02
16	Assurance	22.To feel there was hope	3.7	17	3.2	(-1.36) .18
17	Proximity	11.To be told about transfer plans when they were being made	3.7	22	2.9	(-2.23) *.03
18	Support	9.To have someone concerned with the family member's health	3.6	14	3.3	(-1.34) .18
19	Comfort	1.To feel accepted by the hospital staff	3.6	4	3.7	(-.58) .56
20	Information	2.To talk to the doctor every day	3.4	14	3.3	(-.41) .68
21	Information	12.To know about the types of staff taking care of the patient	3.4	17	3.2	(-.82) .41
22	Proximity	6.To have visiting times start on time	3.4	4	3.7	(-1.07) .29
23	Proximity	16.To help with the patient's physical care	3.4	14	3.3	(-.74) .46
24	Proximity	24.To have visiting hours changed for special needs	3.4	21	3.0	(-.95) .34
25	Support	21.Explanation of the environment	3.3	29	2.6	(-2.04) *.04
26	Support	5.To have directions of what to do at the bedside	3.3	26	2.8	(-1.89) .06
27	Information	23.To have a specific person to call at the hospital when not there	3.2	22	2.9	(-.69) .49
28	Support	15.To have friends nearby for support	3.1	22	2.9	(-.83) .41
29	Proximity	4. To talk about feelings	3.0	22	2.9	(-.38) .71
30	Comfort	19.To have a telephone in the waiting room	2.4	30	2.5	(-.53) .60

**Significant at P=<* .05 Paired Wilcoxon signed-rank test

Table 4. 22: CCFNI and NMI paired analysis of means and significance by domains for families of the control unit

Domains	Maximum Score	CCFNI (n=9) %	NMI (n=9) %	(Z) *P*
1.Support	24	23.7 (99)	19.9 (83)	(-.2.37) *.02
2.Comfort	8	5.9 (75)	6.2 (78)	(.59) .68
3.Assurance	28	26.6 (95)	24.3 (87)	(-2.00) *.04
4.Information	24	21.5 (90)	19.8 (83)	(-1.19) .21
5.Proximity	36	29.2 (81)	26.7 (74)	(-.83) .41

*Significant at *P*=≤ 0.05 Paired Wilcoxon signed-rank test

Four items decreased and showed statistically significance differences between the CCFNI and NMI. They included, *to be called at home about changes in the patient's condition (P*=.03) and *to be told about transfer plans when they are being made (P*=.03) both from the proximity domain and *explanation of the environment (P*=.04) and *to be told about other people that could help with problems (P*=.02) from the support domain.

Two items that were ranked high on the CCFNI and decreased on the NMI were the third highest need on the CCFNI: *to know the prognosis* that now ranked 17th on the NMI. The second item was *to talk about the possibility of the patient's death.*

The comparison by the domains (Table 4 .22), showed improvement in the domain of comfort (75% to 78%); however the domains of information (90 % to 83%), proximity (81% to 74%), support and assurance decreased post-test, with significance in the assurance (95% to 87%; *P* = .04) and support (99% to 83%; *P* = .02) domains.

4.6.3 Summary

The comparison of the paired analysis of the CCFNI and NMI completed by the families of the active and control units pre- and post-test are summarised in Table 4.23. The purpose of the analysis was to compare perception of needs of both cohorts of families pre-test and to determine if families felt their needs were met post-test. The results showed that the improvements in perception of family needs demonstrated in the active unit were not matched in the control unit.

Table 4. 23: Summary of the analysis and results of the CCFNI compared to the NMI for the families of the active and control units

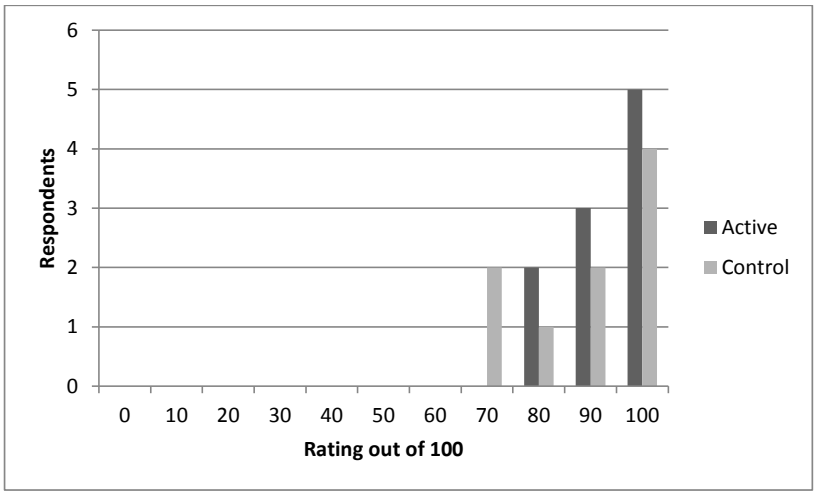
Time frame	Participants	Purpose	Analysis	Results
Post-test	Families of the active unit	To see if families perceived that their needs had been met	Tables 4.19 Comparing the means of CCFNI (Column A) completed pre-test to means of NMI (Column B) completed post-test. Analysis used non-parametric testing; paired Wilcoxon signed -rank test. Significance shown in column C Table 4.20 Paired analysis of CCFNI and NMI by domains Analysis used paired Wilcoxon signed-rank test and the change in percentage pre- to post-test	Family needs were met : Talk about feelings To have directions of what to do at the bedside. Family needs were not met in: Knowing the prognosis To talk about the possibility of the patient's death. The support and comfort domains showed improvement on the NMI The assurance, information and proximity domains decreased post-test
	Families of the control unit	To see if families perceived that their needs had been met	Table 4.21 Comparing the means of CCFNI (Column A) completed pre-test to means of NMI (Column B) completed post-test. Analysis used non-parametric testing; Paired Wilcoxon signed-rank test. Significance shown in column C Table 4.22 Paired analysis of CCFNI and NMI by domains. Analysis used paired Wilcoxon signed-rank test and the change in percentage pre- to post-test	Family needs were not met : To be called at home about changes in the patient's condition To be told about transfer plans when they were being made To be told about other people that could help with problems Explanation of the environment. The comfort domain was the only domain to show improvement The assurance and support domains showed significant deterioration The changes noted in the Active Unit were not matched in the Control Unit

4.7 Results and analysis of the Family Feedback Survey

The FFS question, *"How likely are you to recommend our service to friends and family if they needed similar care or treatment?"* was given to the family member along with the NMI

when the patient was discharged from the ICU. The results for both the active and control unit families are shown in Figure 4.2.

Figure 4. 2: Results of the FFS



Ten families in the active unit and nine families in the control unit completed the question. The mean, standard deviation and significance were measured using non-parametric testing-Mann-Whitney U test (Table 4.24). This showed the distribution of how likely the families were to recommend the service to friends and family was the same across both units with significance of P=.60.

Table 4. 24: Comparison of the results of the FFS between the active and control unit families

Unit	Participants (n=)	Mean	Standard deviation	(Z) *P*
Active	10	93	8.2	(0.61) .60
Control	9	89	12.7	(0.61) .60

P, Mann-Whitney U test

4.8 Results and analysis of the clinical and healthcare outcomes

The clinical and healthcare outcomes were measured by: patient muscle measurements, ventilator hours, length of stay in the ICU and hospital and mortality.

4.8.1 Muscle measurements

Patients that had a minimum of two measurements taken during their ICU admission had their results included in the study. This was (n=14; 74%), of which (n=8; 80%) were from the active unit and (n=6; 67%) were from the control unit. Measurements were taken from the right and left, forearm, upper arm and thigh, in centimetres using both a tape measure and ultrasound.

Analysis was undertaken in two ways; first, there was a comparison of each muscle group for the participants in each unit, pre- and post-study using paired Wilcoxon signed-rank test (Table 4.25); second, the comparison of change value of the mean of patients' muscle measurements between the first and second measurement for the participants in each unit, pre- and post-study using the Mann-Whitney U test (Table 4.26).

The results of the analysis shown in Table 4.25, for the paired comparison between the patients' first and second muscle measurements demonstrated that there was muscle wasting for the patients of both units.

Table 4. 25: Paired comparison between the patients' first and second muscle measurements

	Muscle Group	Active unit (n=8)			Control unit (n=6)		
		Mean	**SD**	**(Z) *P***	**Mean**	**SD**	**(Z) *P***
Pair 1	Right Forearm	24.6	3.8	(-2.59)	22.1	2.3	(-.73)
	Right Forearm	22.9	3.5	.01	21.5	3.5	.47
Pair 2	Left Forearm	24.9	3.2	(-1.40)	23.4	2.1	(-1.07)
	Left Forearm	23.8	4.9	.16	22.8	3.4	.29
Pair 3	Right Upper	28.0	6.1	(-.77)	29.4	3.2	(-.74)
	Right Upper	27.6	4.9	.44	28.4	3.6	.46
Pair 4	Left Upper	28.8	5.9	(-1.78)	29.1	4.0	(-1.09)
	Left Upper	26.8	4.1	.08	28.4	4.3	.28
Pair 5	Right Thigh	51.0	7.4	(-1.99)	51.2	8.3	(-1.84)
	Right Thigh	48.2	5.7	.05	47.8	6.6	.07
Pair 6	Left Thigh	50.3	7.9	(-2.38)	51.1	8.2	(-1.48)
	Left Thigh	46.9	5.3	.02	48.5	6.1	.14

*Significant at $P=\leq .05$ paired Wilcoxon signed-rank test

The results of the analysis in Table 4.26 comparing the change value of the mean of patients' muscle measurements showed that there was no difference between the active and control unit patients, with both cohorts losing muscle mass. Although this was not the desired

outcome, it was not detrimental to the patient having family assisting with the exercises. It is contended, that these findings reflect the severity of the patients' illnesses and support that patients develop ICUAW.

Table 4. 26: Comparison of change value of the mean of patients' muscle measurements

Muscle Group	Active unit (n=8)		Control unit (n=6)		Significance
	Mean	SD	Mean	SD	(Z) *P*
Right Forearm	-1.7	1.8	-0.6	2.0	(-1.39) .18
Left Forearm	-1.0	2.9	-0.7	1.6	(-1.11) .28
Right Upper arm	-0.4	1.5	-1.0	1.7	(-.66) .57
Left Upper arm	-1.9	3.5	-0.7	1.1	(-.46) .66
Right Thigh	-2.8	3.8	-3.3	3.3	(-.20) .85
Left Thigh	-3.4	4.2	-2.6	4.1	(-.58) .57

*Significant at $P=\leq .05$ Mann-Whitney U test

Table 4. 27: Summary of the analysis and results of the patients' muscle measurements

Time frame	Participants	Purpose	Analysis	Result
Post-test	Patients of the active and control units	To determine if there was a reduction in muscle wasting in the patients receiving the intervention of family assisted passive exercises in the active unit. Compared to the patients receiving passive exercises from nurses in the control unit	Table 4.25 Comparing the means of two muscle measurements in centimetres for each muscle group, and by unit Analysis using paired Wilcoxon signed-rank test	The results demonstrated that the distribution of change was the same across both units
			Table 4.26 Comparing the means of differences between the first and second muscle measurements in centimetres for each muscle group, and by unit Analysis using Mann-Whitney U test	The results of the analysis comparing the change value of muscle measurement showed that there was no difference between the active and control unit patients.

4.8.2 Ventilator hours, length of stay and mortality

Although the focus of the study was the patients and the families that completed all parts of the study, as there was a large number of participants lost to follow-up, the data for all of the

enrolled patients (Table 4.28) and those lost to follow-up (Table 4.29) were examined. This was to determine whether the reasons for the attrition could be concluded from the data. What could be determined was that there was a wide variation in ventilator hours, length of stay in ICU and hospital length of stay and mortality was high in the patient cohorts (Tables 4.28 to 4.31). Length of stay in ICU was less in those lost to follow-up and this could be attributed to the increased rate of mortality in this cohort of patients (Tables 4.31).The results of the remaining patients (Table 4.30) shows the mean ventilator hours and length of stay in ICU were longer in the active unit, whereas the mean length of stay in the hospital was longer and the mortality rate (Table 4.31) was higher in the control unit .The distribution of ventilator hours, length of stay in the ICU and the hospital is the same across both units.

Table 4. 28: Clinical outcomes and healthcare efficiency measurements for all enrolled patients

	Total (n=30)				**Active unit (n=12)**				**Control unit (n=18)**			
Measure	Mean	SD	Range	Med	Mean	SD	Range	Med	Mean	SD	Range	Med
Ventilator Hours	269	221	20-1021	226	303	246	33-1021	237	245	208	20-815	197
Length of Stay ICU (Days)	19	15	2-56	14	23	16	2-56	20	16	13	5-54	12
Length of Hospital Stay (Days)	66	96	6-324	26	74	105	8-324	36	61	92	6-308	26

Table 4. 29: Clinical outcomes and healthcare efficiency measurements of patients lost to follow-up

Measure	**Total (n=11)**				**Active unit (n=2)**				**Control unit (n=9)**			
	Mean	SD	Range	Med	Mean	SD	Range	Med	Mean	SD	Range	Med
Ventilator hours	247	27	104-815	197	236	55	197-274	236	249	30	104-815	163
Length of Stay ICU (Days)	13	9	6-39	9	10	3	8-12	10	14	9	6-39	9
Length of Hospital Stay (Days)	20	32	6-57	19	10	13	8-12	10	23	33	6-57	19

Table 4. 30: Clinical outcomes and healthcare efficiency measurements of remaining patients

Measure	Total (n=19)				Active unit (n=10)				Control unit (n=9)				
	Mean	SD	Range	Med	Mean	SD	Range	Med	Mean	SD	Range	Med	***P***
Ventilator hours	281	236	20-1021	232	316	269	33-1021	237	242	202	2-638	218	.49
Length of Stay ICU (Days)	22	16	2-56	18	26	16	2-56	22	19	16	5-54	15	.24
Length of Hospital Stay (Days)	93	113	10-324	45	87	112	21-324	45	99	120	10-308	49	.84

Table 4. 31: Mortality of patients

	Total n (%)	**Active unit n (%)**	**Control unit n (%)**
All patients	n=30 11 (37)	n=12 3 (25)	n=18 8 (44)
Lost to follow up	n=11 6 (55)	n=2 2 (100)	n=9 4 (44)
Remaining patients	n=19 5 (26)	n=10 1 (10)	n=9 4 (44)

4.9 Conclusion

This chapter has presented the demographics of the patients and their families. Those that enrolled, those lost to follow-up and the remaining families that completed all parts of the study.

The results of the CCFNI have demonstrated that pre-test both the active and the control units responses to the CCCFNI showed that the nurses did not rank family needs as highly as the families. Post-test, the nurses' perceptions were more aligned with the families with greater improvement in the active unit.

The comparison of the families' results of the CCFNI to the NMI showed that the improvements in the active unit were not matched in the control unit.

The results from the FSS were positive for both units.

The results of the patient's muscle measurements demonstrated that in this cohort of patients, muscle wasting occurred. The other healthcare measure showed that ventilator hours, length of stay in the ICU and the hospital and mortality were all higher than the usual measures for the ICUs at the study site.

The following chapters will present the results of the mNSS and the focus groups conducted with the nurses prior to the discussion chapter which will determine whether the research questions have been answered.

Chapter 5 The experiences of the nurses

5.1 Introduction

Chapter 4 presented the results for the family, patients and healthcare system. This included the results of the CCFNI completed by the nurses that were a measure of family outcomes. This chapter presents the results of the mNSS used to measure nursing outcomes.

This chapter is structured as follows. First, an overview of the measurement instrument, used to answer the research question for the nurses is presented (Table 5.1). This is followed by the survey distribution process to the nurses (section 5.2) and then the nurses' demographics are presented by years nursing and years nursing in ICU (section 5.3). The results of the mNSS completed by the nurses of both the active and control units are presented pre- and post-test; comparing between the units and by years of nursing and working in ICU (section 5.4). The chapter concludes by summarising the findings (section 5.5).

5.2 Focus on the experiences of the nurses

The focus of this chapter is upon the experiences and perceptions of the nurses in relation to stressors. Table 5.1 below shows the links between the research question, instruments, timeframe and purpose of analysis.

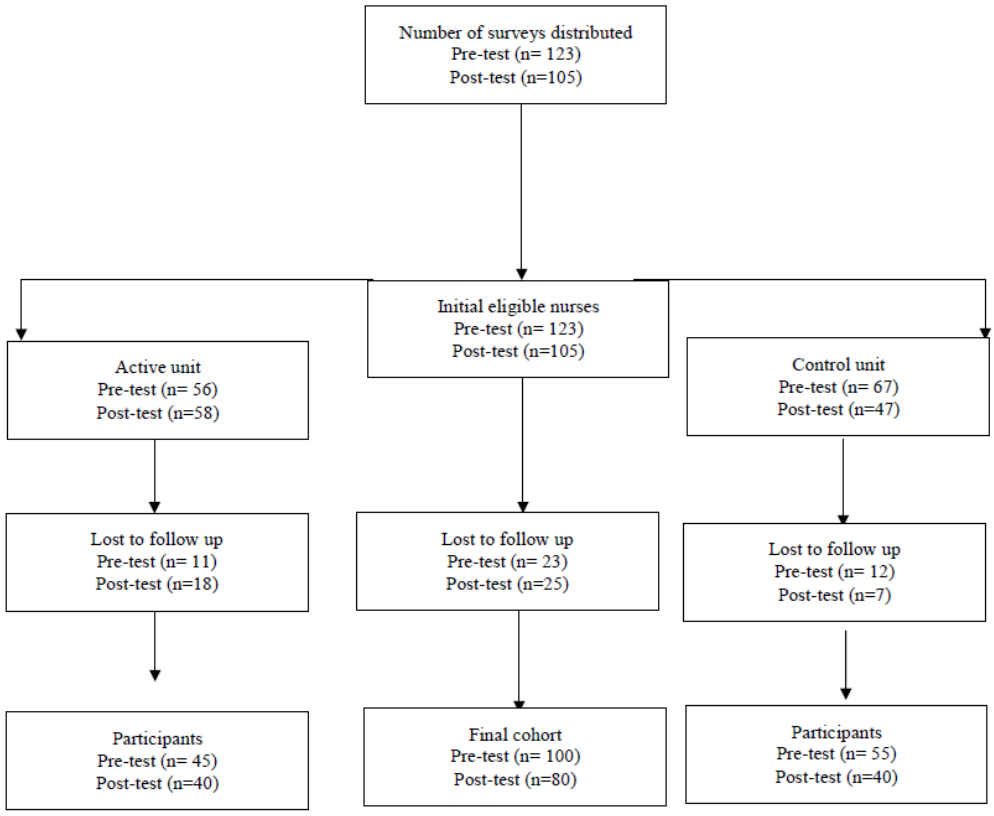
Table 5. 1: Measurement instrument used to address the research question

Question	Instrument	Participants	Timeframe	Purpose
Can family assisted passive exercises on unconscious patients in an Intensive Care Unit achieve better outcomes for the nurses?	Modified Nursing Stress Scale (mNSS)	Nurses of the active and control units	Pre- and post-test	To determine: What items and factors nurses found, most and least stressful. Whether a PFCC intervention could improve nurses' workplace stress and satisfaction Whether there was a difference in stress levels depending on years nursing and years nursing in ICU

5.3 Survey distribution process

The surveys were distributed in paper form to the nurses of the active and control units by the CNEs in each of the Units. The completed forms were returned in envelopes to a central collection box in each unit. The process was the same for the distribution of the CCFNI and mNSS, but this chapter is only presenting the results and analysis of the data for the mNSS,

Figure 5. 1 : Survey distribution process



As shown in Figure 5.1 there were a total of (n=100; 81%) surveys returned from those distributed to the nurses in both units, pre-test. The return rate was (n= 45; 80%) from the nurses in the active unit and (n=55; 82%) from the nurses in the control unit. At completion of the study (n=80; 76%) surveys were returned from those distributed. The return rate was (n=40; 69%) from the nurses in the active unit and (n=40; 85%) from the nurses in the control unit.

As already discussed in Chapter 1 and 3 the study took place over a 12 month period, because of this and the frequency with which nurses change in the ICU setting the surveys were not matched. This can be seen as a limitation of the study design.

5.4 Demographics

The demographics of the nurses for the active and control units were examined pre- and post-test for years of nursing experience and years working in ICU to determine the skill mix. The rationale for this was to compare the findings of the mNSS against years of service to determine if junior and senior nurses experienced stressors in the workplace the same, or differently.

5.4.1 Years nursing

The years of nursing were divided into 0-3 years, 4-6 years, 7-10 years and greater than 10 years. Table 5.2 shows the number and percentage of nurses that fell into each of these groups, pre- and post-test by both the active unit and control units.

Table 5. 2: Years nursing

Years Nursing	Active (n=45) pre-test		Control (n=55) pre-test		Active (=40) post-test		Control (n=40) post-test	
0-3	10	22%	8	15%	6	15%	6	15%
4-6	10	22%	12	20%	12	30%	10	25%
7-10	12	27%	17	32%	6	15%	13	32%
>10	13	29%	18	33%	16	40%	11	28%

This showed that the single biggest cohort by years of nursing was those who had been nursing for longer than 10 years. In the active unit this was (n=13; 29%) pre-test and (n=16;

40%) post-test. In the control unit this was (n=18; 33%) pre-test which reduced to (n=11; 28%) post-test.

Comparing the skill mix by classifying less experienced nurses as zero to six years, and more experienced staff as nursing for more than seven years, then the split was relatively equal for junior and experienced staff. In the active unit, (n= 20; 44%) of the nurses had been nursing less than six years pre-test and (n=18; 45%) post-test and (n=25; 56%) had been nursing greater than seven years pre-test and (n=22; 55%) post-test. In the control unit (n=20; 35%) of the nurses had been nursing less than six years pre-test and (n=16; 40%) post-test and (n=35; 65%) greater than seven years pre-test and (n=24; 60%) post -test.

5.4.2 Years nursing in ICU

The years of nursing in ICU was also divided into 0-3 years, 4-6 years, 7-10 years and greater than 10 years. Table 5.3 shows the number and percentage of nurses that fell into each of these groups, pre- and post-test by both the active unit and control units.

Table 5. 3: Years nursing in ICU

Years ICU	Active (n=45) pre-test		Control (n=55) pre-test		Active (n=40) post-test		Control (n=40) post-test	
0-3	19	42%	18	33%	18	45%	9	22%
4-6	9	20%	15	27%	7	17%	13	33%
7-10	11	24%	13	24%	4	10%	12	30%
>10	6	14%	9	16%	11	28%	6	15%

This showed the single biggest cohort of nurses by years in ICU was the novice level of zero to three years for both the active and control units. In the active unit this was (n=19; 42%) pre-test and (n=18; 45%) post-test. In the control unit this was (n=18; 33%) pre-test and (n=9; 23%) post-test.

Comparing the skill mix by classifying less experienced nurses as zero to six years in ICU and more experienced staff as nursing in ICU for more than seven years; demonstrated that the staff were less experienced in ICU nursing. In the active unit (n=28; 62%) of the nurses had been nursing less than six years in ICU pre-test and (n=25; 62%) post-test; whereas (n=17; 38%) had worked greater than seven years in ICU pre-test compared to (n=15; 38%)

post-test. In the control unit (n=33; 60%) of the nurses had been nursing less than six years in ICU pre-test and (n=22; 55%) post-test; whereas (n=22; 40%) had worked greater than seven years in ICU, pre-test compared to (n=18; 45%) post-test.
This shows that across the nurses from the active unit and the control unit there was: minimal difference between the two cohorts for years of nursing and years working in ICU nursing; and minimal change from the pre-test to the post-test period in relation to this skill mix. This indicated that the units were suitable for a comparative study.

5.5 Modified Nursing Stress Scale

The data from the mNSS were analysed using descriptive and inferential statistics. The means of the individual items, as well as the eight factors that the items are categorised into, were analysed to identify what was perceived as the highest and lowest workplace stressors. This was examined pre- and post-test and comparisons made between the two units. The results were also analysed, looking at the years of nursing and years nursing in ICU to see if these factors impacted on perception of workplace stressors.

This section presents the complete results of the mNSS by active and control units pre- and post-test. The data in Table 5.4, presents the mean score for each individual stressor, as well as the mean score for each of the eight factors that were an aggregate of the item scores within each factor. Non-parametric analysis was with the Mann-Whitney U test.
The estimate of reliability for the study specific questions was determined using Cronbach's alpha to test, internal consistency as discussed in Chapter 3.

5.5.1 Analysis of the mNSS results pre-test

At baseline, pre-test there was little difference between the units in regards to the highest and lowest scoring individual stressors and factors as shown in Table 5.4.

5.5.1.1 Highest stressors

The stressors with the highest mean score for both the active and control units were from: Factor 1, death and dying, including *watching a patient suffer* and *performing procedures that patients experience as painful;* and from Factor 6, workload, including *not enough staff to adequately cover the unit* and *unpredictable staffing and scheduling*

Table 5. 4: mNSS comparison of mean results and significance

Factors and individual items	Active unit (n=45) mean pre-test	Active unit (n=40) mean post-test	Z/*P*	Control unit (n=55) mean pre-test	Control unit (n=40) mean post-test	Z/*P*
Factor 1: Death and dying						
Performing procedures that patients experience as painful	2.4	2.4	(-.04) .97	2.6	2.4	(-1.01).32
Feeling helpless in the case of a patient who fails to improve	2.1	2.2	(-.50) .62	2.3	2.2	(-1.09).27
Listening or talking to a patient about his/or her approacching death	2.4	2.4	(-.09) .93	2.4	2.4	(-.08).94
The death of a patient	2.3	2.2	(-.03) .97	2.4	2.3	(-.97) .33
The death of a patient with who you developed a close relationship	2.1	2.0	(-.41) .68	2.2	1.9	(-2.21) *.03
Physician not being present when a patient dies	1.8	1.9	(-.04) .97	2.3	2.0	(-1.62) .11
Watching a patient suffer	2.6	2.5	(-1.03) .31	2.7	2.5	(-1.42) .16
Death and dying score	**15.8**	**15.5**	**(-.38) .70**	**17.0**	**15.9**	**(-1.61) .11**
Factor 2: Conflict with physicians						
Criticism by a physician	2.1	2.0	(-.93) .35	2.1	1.9	(-1.66) .10
Fear of making a mistake in treating a patient	2.3	2.2	(-.25) .81	2.5	2.3	(-1.23) .22
Disagreement concerning treatment of a patient	2.0	2.0	(-.03) .98	2.1	2.1	(-.12) .91
Making a decision concerning a patient when the physician is unavailable	2.0	2.0	(-.64) .53	2.1	2.1	(-.33) .74
Conflict with physicians score	**8.4**	**8.1**	**(-.49) .62**	**8.8**	**8.4**	**(-.74) .46**
Factor 3: Inadequate preparation to deal with the emotional needs of patients and their families						
Feeling inadequately prepared to help with the emotional needs of a patient's family	2.2	2.2	(-.01) .99	2.1	2.2	(-.99) .32
Being asked a question by a patient for which I do not have a satisfactory answer	2.3	2.3	(-.25) .80	2.3	2.2	(-1.43) .15
Feeling inadequately prepared to help with the emotional needs of a patient	2.1	2.1	(-.13) .90	2.1	2.1	(-.16) .87
Inadequate preparation Factor Score	**6.6**	**6.6**	**(-.08) .94**	**6.4**	**6.4**	**(-.67) .50**
Factor 4: Lack of staff support						
Lack of opportunity to talk openly with other unit personnel about problems on the Unit	2.0	1.8	(-1.01) .31	2.0	2.1	(-.60) .55
Lack of opportunity to share experiences and feelings with other personnel on the Unit	1.8	1.7	(-1.04) .30	2.0	1.9	(-.12) .91
Lack of an opportunity to express to other personnel on the unit my negative feelings toward patients	1.7	1.5	(-1.87) .06	1.8	1.9	(-1.03) .30
Lack of support score	**5.5**	**4.9**	**(-1.35) .18**	**5.8**	**5.9**	**(-.99) .32**
Factor 5: Conflict with other nurses and supervisors						
Conflict with a supervisor	1.6	1.4	(-1.68) .09	1.7	1.8	(-.79) .43
Floating to other units that are short staffed	2.3	2.0	(-1.75) .08	2.5	2.3	(-1.23) .22
Difficulty with working with a particular nurse (or nurses) outside the unit	1.7	1.4	(-2.77)*.006	1.7	1.8	(-1.22) .22

Factors and individual items	**Active unit (n=45) mean pre-test**	**Active unit (n=40) mean post-test**	**Z/*P***	**Control unit (n=55) mean pre-test**	**Control unit (n=40) mean post-test**	**Z/*P***
Criticism by a supervisor	1.7	1.6	(-1.27) .20	1.7	1.9	(-1.29) .20
Difficulty with working with a particular nurse /nurses on the unit	1.8	1.6	(-1.53) .13	1.8	1.9	(-.85) .40
Conflict with other nurses score	**9.1**	**7.8**	**(-2.75)*.006**	**9.4**	**9.7**	**(-.59) .56**
Factor 6: Workload						
Breakdown of a computer	1.9	1.8	(-1.43) .15	2.1	2.0	(-1.21) .23
Unpredictable staffing and scheduling	2.4	2.4	(-.26) .80	2.7	2.6	(-.56) .57
Too many non-nursing tasks required such as clerical work	2.2	2.1	(-.63) .53	2.3	2.4	(-.59) .56
Not enough time to provide emotional support to a patient	2.2	2.2	(-.35) .73	2.4	2.5	(-.71) .48
Not enough time to complete all my nursing tasks	2.2	2.1	(-.81) .42	2.3	2.5	(-1.29) .20
Not enough staff to adequately cover the unit	2.7	2.4	(-.1.97) *.05	2.7	2.9	(-1.04) .30
Workload score	**13.6**	**12.9**	**(-1.31) .19**	**14.4**	**14.8**	**(-.49) .62**
Factor 7: Uncertainty concerning treatment						
.Inadequate information from a physician regarding the medical condition of a patient	2.0	2.1	(-.85) .39	2.4	2.3	(-1.25) .21
A physician ordering what appears to be inappropriate treatment for a patient	1.9	1.8	(-.86) .39	2.0	2.0	(-.35) .73
A physician not being present in a medical emergency	1.6	1.4	(-1.50) .13	1.6	1.6	(-.56) .57
Not knowing what a patient or a patient's family ought to be told about the patient's condition and its treatment	2.0	2.1	(-.65) .52	2.2	2.1	(-.40) .69
Uncertainty regarding the operation and functioning of specialised equipment	2.0	2.0	(-.19) .85	2.2	2.0	(-1.41) .16
Uncertainty concerning treatment score	**9.6**	**9.4**	**(-1.33).90**	**10.4**	**10.0**	**(-.54) .59**
Factor 8: Study specific questions						
Teaching family members	2.1	2.1	(-.55) .58	2.1	2.1	(-.30) .77
Talking to family members	2.2	2.6	(-.1.85) .07	2.6	2.7	(-.73) .46
Delivering passive exercises to patients	1.7	1.8	(-.62) .54	2.0	2.0	(-.16) .88
Discussing clinical care with family members	2.1	2.4	(-1.34) .18	2.4	2.5	(-.58) .56
Study specific questions score	**8.1**	**8.9**	**(-1.53) .13**	**9.1**	**9.2**	**(-.27) .79**

*Significance at $P \leq .05$ Mann-Whitney U test

5.5.1.2 Lowest stressors

The stressors with the lowest mean score included items from Factor 5, conflict with other nurses and supervisors, including: *conflict with a supervisor* and *difficulty with working with a particular nurse (or nurses) outside the unit* and Factor 7, uncertainty concerning treatment, *a physician not being present in a medical emergency.*

5.5.1.3 Difference in perception of stressors between the active and control unit nurses

The greatest differences pre-test were: the control unit, who ranked, *physician not being present when a patient dies*, from Factor 1, death and dying, and *talking to family members*, from Factor 8, study specific questions. These were ranked higher than the active unit.

5.5.2 Analysis of the mNSS results post-test

The pre- and post-test survey results were analysed using non-parametric testing. This was to assess if there had been any significant change in the stressors after the intervention of the family assisted passive exercising. The individual items and the factors were tested for significance using the Mann-Whitney U test.

In the active unit two items improved, showing a statistically significant difference ($P=\leq .05$). One item was from Factor 5, conflict with other nurses and supervisors, *difficulty with working with a particular nurse (or nurses) outside the unit* and one item was from Factor 6, workload, *not enough staff to adequately cover the unit.*

In the control unit one item improved showing a statistically significant difference ($P=\leq .05$). This item was from Factor 1, death and dying: *the death of a patient with who you developed a close relationship.*

The results of the factors have been extracted from Table 5.4 and are summarised in Table 5.5 for the active unit and Table 5.6 for the control unit.

This shows that in the active unit there was a statistically significant improvement in Factor 5, conflict with other nurses and supervisors. The mean decreased from 9.1 to 7.8 ($P=.006$).

Pre- to post-test, the mean score for six of the eight factors improved (reduced); Factor 3, inadequate preparation, showed no change and Factor 8, study specific questions, increased (worsened).

Table 5. 5: Active unit mNSS results by factors pre- to post test

Factor	Maximum score	How did the mean score change pre- to post-test?	Z/*P*
1.Death and dying	28	15.8 → 15.5	(-.38) .70
2. Conflict with physicians	16	8.4 →8.1	(-.49) .62
3. Inadequate preparation	12	6.6 → 6.6	(-.08) .94
4. Lack of support	12	5.5 → 4.9	(-1.35) .18
5. Conflict with other nurses	20	9.1 → 7.8	(-2.75) *.006
6. Workload	24	13.6 → 12.9	(-1.31) .19
7. Uncertainty	20	9.6 → 9.4	(-1.33) .90
8.Study specific questions	16	8.1 →8.9	(-1.53) .13

*Significance at *P*= ≤.05 Mann-Whitney U test

The changes noted in the active unit, were not matched in the control unit (Table 5.6). Pre- to post-test, the mean score for only three of the factors improved; Factor 3 showed no change and four of the factors increased (worsened).

Table 5. 6: Control Unit mNSS results by factors

Factor	Maximum score	How did the mean score change pre- to post-test?	Z/*P*
1. Death and dying	28	17.0→ 15.9	(-1.61) .11
2. Conflict with physicians	16	8.8 →8.4	(-.74) .46
3. Inadequate preparation	12	6.4→ 6.4	(-.67) .50
4. Lack of support	12	5.8 → 5.9	(-.99) .32
5. Conflict with other nurses	20	9.4 → 9.7	(-.59) .56
6. Workload	24	14.4 → 14.8	(-.49) .62
7. Uncertainty	20	10.4→ 10.0	(-.54) .59
8. Study specific questions	16	9.1→ 9.2	(-.27) .79

P= Mann-Whitney U test

5.5.3 Comparison of the results of the mNSS between the nurses of the active and control units

Table 5.7 presents the aggregated results of the mNSS from the nurses of the active and control units pre- and post-test. The results include the mean score from the possible score of 148, the standard deviation and range. The mean score was lower in the active unit pre-test, with a score of 77.2 compared to 81.5 in the control unit. There was improvement in both

units for the mean score post-test, however the active unit improved by a mean score of 3.7 to 73.5, the control unit by 2.6 to 78.9

Table 5. 7: Mean results of mNSS from all respondents

Active Unit (n=45) pre-test			Active Unit (n=40) post-test			Control Unit (n=55) pre-test			Control Unit (n=40) post-test		
Mean	SD	Range	Mean	SD	Range	Mean	SD	Range	Mean	SD	Range
77.2	2.8	43-107	73.5	7.1	51-98	81.5	9.9	61-133	78.9	4.9	59-108

5.5.4 Comparison of the results of the mNSS by years of nursing experience and years nursing in ICU

Table 5.8 presents the mean score, standard deviation and range for the nurses of the active and the control units by years of nursing experience. Pre-test the more junior staff in both units had a marginally higher (worse) mean score on the mNSS than the more senior staff. In the 0-3 years of nursing group, this was 77.5 in the active unit and 84.0 in the control unit.

Table 5. 8: Mean results of mNSS by years of nursing

Years Nursing	Active unit (n=45) pre-test			Active unit (n=40) post-test			Control unit (n=55) pre-test			Control unit (n=40) post-test		
	Mean	SD	Range	Mean	SD	Range	Mean	SD	Range	Mean	SD	Range
0-3	77.5	15.6	43-97	↓70.5	6.4	56-98	84.0	9.2	64-133	↓74.4	2.8	66-88
4-6	79.2	6.4	61-97	↓73.6	6.4	58-95	81.8	9.9	61-108	↑83.1	33.2	61-108
7-10	77.5	14.8	53-107	↓74.3	4.2	63-81	81.1	7.1	68-102	↑81.9	11.31	66-102
>10	74.7	7.8	63-85	↑75.6	3.5	51-93	79.1	9.9	65-115	↓76.2	4.2	59-92

Post-test the mean scores reduced in the active unit in all categories (as indicated by the arrows in the table) except the most senior group of nurses where the mean increased from 74.7 to 75.6. In the control unit there was improvement in the most junior cohort of nurses, down from a mean of 84.0 to 74.4 and the most senior cohort of nurses down from a mean of 79.1 to 76.2

Table 5.9 presents the mean score, standard deviation and range for the nurses of the active and the control units by years of ICU nursing experience. Pre-test the two more junior cohorts (0-3 and 4-6 years) of nurses had higher means scores than their more senior colleagues. For

the active unit this was 79.5 (0-3) and 80.4 (4-6) and for the control unit 83.3 (0-3) and 79.6 (4-6).

Table 5. 9: Mean results of mNSS by years of nursing in ICU

Years ICU	Active unit (n=45) pre-test			Active unit (n=40) post-test			Control unit (n=55) pre-test			Control unit (n=40) post-test		
	Mean	SD	Range	Mean	SD	Range	Mean	SD	Range	Mean	SD	Range
0-3	79.5	18.4	43-107	↓72.5	9.2	56-98	83.3	16.3	64-133	↓81.9	9.2	61-108
4-6	80.4	11.3	61-99	↓74.5	4.2	58-95	79.6	1.4	61-108	↓79.4	17.7	61-102
7-10	71.5	7.1	53-85	↑76.8	2.8	72-82	80.4	4.9	69-87	↓79.2	17.0	53-102
>10	77.5	2.8	74-83	↓75.2	9.9	51-91	79.4	6.4	65-115	↓78.7	4.2	59-92

Post-test there was an overall improvement for the active unit (as indicated by the arrows) with the exception of the 7-10 years cohort of nurses, whose mean increased from 71.5 to 76.8. The greatest improvement was in the 0-3 cohort where the mean decreased by 7 points from 79.5 to 72.5 In the control unit the mean improved in all cohorts but not to the same degree, and the most improved was also the 0-3 cohort which improved by 1.4 points from 83.3 to 81.9 points.

The mNSS results from both the active and the control units were combined pre-test and analysed using non-parametric rank correlation to determine whether the years of experience in nursing or in ICU nursing had any significance in relation to the stressors.

The results presented in Table 5.10 show that, not unexpectedly there was a positive correlation between years of nursing experience and years nursing in ICU (P= < .0001). Six items and two factors showed significant negative correlation with years of nursing experience. The strongest item negative correlation was: *not knowing what a patient or a patient's family ought to be told about the patient's condition and its treatment* (P= < .001).The strongest factor correlation related to Factor 7, uncertainty concerning treatment (P=.01). So again, not unexpectedly, with greater years of nursing experience, self-perceived stress around uncertainty and patient communication related items tended to decrease.

Table 5. 10: The role of nursing experience: correlation analysis - active and control units combined

Item	Rho	*P*
ICU experience	= 0.81	*<.0001
9. Watching a patient suffer	= -0.27	*.008
11. Fear of making a mistake in treating a patient	= -0.21	*.04
15. Being asked a question by a patient for which I do not have a satisfactory answer	= -0.29	*.003
17. Lack of opportunity to talk openly with other unit personnel about problems on the Unit	= -0.20	*.04
34. Not knowing what a patient or a patient's family ought to be told about the patient's condition and its treatment	= -0.42	*<.0001
35. Uncertainty regarding the operation and functioning of specialised equipment	= -0.22	*.03
Factor		
Factor 3: Inadequate preparation	= -0.23	*.02
Factor 7: Uncertainty concerning treatment	= -0.25	*.01

*Significance at *P*= ≤.05 non-parametric rank correlation

5.6 Conclusion

This chapter has presented the analysis and results of the mNSS, which are summarised in Table 5.12.

Table 5. 11: Summary of the analysis and results of the mNSS

Time frame	Participants	Purpose	Analysis	Result
Pre-test	Nurses active and control units	To determine what items and factors nurses found most and least stressful and whether there was any difference between units	Section 5.4.1 Table 5.4 Frequency analysis of means of items and factors. Significance tested using Mann-Whitney U test	Pre-test there was little difference between the units in regards to the highest and lowest scoring individual stressors and factors
Pre- and post-test	Nurses active and control units	To determine if there had been any significant change in the stressors after the intervention of the family assisted passive exercising	Section 5.4.2 Tables 5.5 and 5.6 Items and factors were analysed using non-parametric Mann-Whitney U test	Six factors improved for the nurses of the active unit; this was not matched for the nurses of the control unit where four of the factors were worse post-test
Pre- and post-test	Nurses active and control units	To determine whether there was a perceived difference in stress levels between the active and the control units and whether there was any changes to stress levels post-test	5.4.3 Table 5.7 Mean results of mNSS from all respondents	Both the active and control units aggregated mean scores improved post-test but with greater improvement in the active unit
Pre- and post-test	Nurses active and control units s	To determine whether there was a difference in stress levels	Section 5.4.4 Table 5.8 and Analysis of means by	Pre-test more junior nurses in both units had marginally higher

Time frame	Participants	Purpose	Analysis	Result
		depending on years of nursing experience and whether there was any difference in levels of stress between units	years of nursing	mean score. Post-test the mean scores reduced in the active unit in all categories except the most senior group of nurses. In the control unit there was improvement in the most junior cohort of nurses and the most senior cohort of nurses
Pre- and post-test	Nurses active and control units	To determine whether there was a difference in stress levels depending on years of ICU nursing experience and whether there was any difference in levels of stress between units	Section 5.4.4 Table 5.9 Analysis of means by years nursing in ICU	Pre-test more junior nurses in both units had higher mean scores. Post-test there was greater improvement in the mean scores for the active unit
Pre-test	Nurses active and control units	Comparison of years nursing to years of ICU nursing experience active and control units combined	Section 5.4.4 Table 5.10 Non-parametric rank correlation	There was a significant negative correlation between nursing experience and years nursing in ICU *P*=<0.0001; and for six items and two factors. The strongest item correlation was Not knowing what a patient or a patient's family ought to be told about the patient's condition and its treatment *P* = <001; the strongest factor correlation related to factor 7, Uncertainty concerning treatment *P* =.01. This was the same across both the active and control units

This concludes the quantitative results. The next chapter presents the perception of the nurses from the focus groups.

Chapter 6 Perceptions of the nurses

6.1 Introduction

Chapters 4 and 5 presented the quantitative results, which were the main measure of outcomes for the study. This chapter presents the findings from the focus groups held with the nurses. The purpose of these focus groups was to first gain greater insight into the nurses' perceptions of ICU families' needs; and second, their perception of the impact of the family assisting with passive exercise on the family, patient, nurses and healthcare system.

Focus groups were chosen, first, as it meant that: more staff members could be canvassed for their opinion. In this case 18 staff participated in the focus groups. To have interviewed 18 staff individually would have been impractical and in any case, unwarranted in terms of robust research application. Second, the structure of focus groups allowed the participants to study the issues collectively and for the researcher to be more observant. This was seen as appropriate given that team work is a focus in the ICU setting. It is however recognised that this can allow quieter members of the team to be passive in discussions and requires the skills of the moderator to ensure that all participants are afforded equal time to speak (Lincoln & Guba 1985, Nyumba et al. 2017).

The chapter commences with Table 6.1 below, which shows: the links between the research questions; the instrument of the focus group; the participants; when the focus groups were held and the purpose of the focus groups.

This is followed by presenting the demographics of the three focus groups (section 6.2); the findings from these groups, which are separated into sub-sections of families, patients and nurses (section 6.3), before the chapter concludes by summarising these findings (section 6.4).

Table 6. 1: Method used to address the research questions

Question	Instrument	Participants	Timeframe	Purpose
Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for the family?	Focus groups	1)Nurses of the active unit 2) Nurses of the control units 3) Nurse educators and managers from both the active and control units	Post-test	To investigate the perceptions of the nurses in relation to the impact of the intervention on the families
Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for the patient?	Focus groups	1)Nurses of the active unit 2) Nurses of the control units 3) Nurse educators and managers from both the active and control units	Post-test	To investigate the perceptions of the nurses in relation to the impact of the intervention on the patients
Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for the nurses?	Focus groups	1)Nurses of the active unit 2) Nurses of the control units 3) Nurse educators and managers from both the active and control units	Post-test	To investigate the perceptions of the nurses in relation to the impact of the intervention on the nurses

6.2 Demographics of the focus groups

There were three focus groups. One group was with the direct care nurses of the active unit, and, a second was with the direct care nurses of the control unit. The third was a combination of nursing managers and educators from the active and the control units. The reason for separating the direct care nurses from the more senior nurses was to encourage them to be more open in their discussion and prevent any potential hierarchy bias that may occur (Nyumba et al. 2017).

In total 18 staff participated in the three groups. The demographics of the groups are presented in Table 6.2 by age, years as a nurse and years as a nurse in ICU.

Table 6. 2: Focus group demographics

Items	Active unit nurses (n=6)			Control unit nurses (n=7)			Managers and educators Active and control units (n=5)		
	Range	Mean	SD	Range	Mean	SD	Range	Mean	SD
Age	28-47	35	6.73	24-42	33	6.90	36-54	44	7.87
Years as a Nurse	6-18	11.16	5.45	1-9	4	3.26	12-33	20	10.21
Years in ICU	2-18	8.33	5.71	1-9	5.71	2.42	7-28	15	8.51

6.2.1 Active unit

The active unit focus group comprised of registered nurses (RNs) that provided direct care to the patients and therefore had daily interactions with the families. Two of these nurses had been members of the pre-test working party. The entire group had been responsible for teaching the family members how to do the passive exercises.

As presented in Table 6.2, the focus group consisted of six participants. The nurses ranged in age from 28 to 47 years. Their years of working as an RN ranged from 6 to 18 years and years working in ICU ranged from 2 to18 years.

6.2.2 Control unit

The control unit focus group comprised of RNs that provided direct care to the patients and therefore had daily interactions with the families. One member had participated in the pre-test working group. All members of the focus group had been responsible for delivering passive exercises to the patient.
As presented in Table 6.2, the group consisted of seven participants. The RNs ranged in age from 24 to 42 years and had worked both as an RN and in the ICU setting from 1 to 9 years.

6.2.3 Managers and educators

The nursing managers' and educators' focus group comprised of the two NUMs and the two CNEs from the active and the control units and the nurse manager that oversaw the four

ICUs. The CNEs had been actively involved in the pre-test working party. The NUMs and nurse manager had been kept informed throughout the study period with individual meetings.

As presented in Table 6.2 their ages ranged from 36 to 54 years. Their years working as an RN ranged from 7 to 28 years, and working in ICU ranged from 7 to 28 years in ICU.

6.2.4 Summary of demographics

The age of the active and control unit nurses was similar (28-47 years in the active unit; compared to 24-42 years of age in the control unit). However the active unit nurses were more experienced both as RNs (6 to 18 years compared to 1 to 9 years in the control unit cohort) as well as working in ICU (2 to 18 years compared to 1 to 9 years). As would be expected the managers and educators were slightly older and were more experienced in the years they had been nursing (12 to 33 years) and years as an ICU nurse (7 to 28 years).

6. 3 Focus group findings

As discussed in Chapter 3, there was a guided discussion in the each of the focus groups. The guided discussion was led by the researcher as the moderator, with the assistance of the ICU CNC.

The sessions used a script of open ended questions (Appendix 10). First, there were ‘engagement questions’, each group was asked the purpose of the study, and what were the differences between the roles of the active and control units. This was to assess that they understood these paradigms.

All participants were able to identify that this was a PFCC study and the aims of the study in relation to the family, patient and nurses. Each group were able to articulate the difference between the active and control units role in the study. That is, the active unit was where the family assisted the nurses with doing the passive exercises and the control unit was where the nurses did the exercises.

Second, the groups were asked ‘exploratory questions’ in relation to the study. In that they were asked what impact did they think the study and passive exercises had on the families,

the patients and the nurses. There was flexibility in relation to the flow of the discussions, but they were brought back on track if the participants digressed from the subject matter.

Finally, before the sessions concluded the groups were asked if there was anything else that they would like to say about the study that had not been covered in the session.

The data reported was guided by the research questions put to participants with a deductive approach based on focus of the study. Analysis used both the word clouds which highlighted words which were then searched for in the three focus groups. Inductive content analysis was used to analyse the transcripts to identify patterns of words and themes to ensure orientation of these findings to previous findings within the study. This was to allow ease of understanding and interpretation (Braun and Clarke, 2006).

The steps to the analysis as discussed in Chapter 3, section 3.5.1.3 were as follows. The groups were taped with the consent of the participants and transcripts made of the sessions. Once the sessions were complete transcript-based analysis was then used as it is reported to be the most rigorous and reliable mode of analysing data (Braun & Clarke 2006; Vaismoradi, Turunen & Bondas 2013). This was a five step process. First, the recordings were each combined into one text document and uploaded into a text management program (N-Vivo) by the researcher. The text management program was used purely to identify prominent words to support the themes. Secondly, the text count and the word-cloud that this program generated were reviewed as a whole to gain an understanding of the variety and scope of the responses. Automatic analysis of the text shows the 'word-cloud' produced which highlights the key points or phrases from participants (Figure 6.1).

Figure 6. 1: Focus group word-cloud

As can be seen the prominent words are: family; families; patient/s; nursing; communication and exercise. This was the same across the three groups and helped to focus the reporting and coding for this chapter.

Thirdly, the text was examined line-by-line to identify the key points from respondents for each of the questions asked. Fourthly, the key points were examined and refined into similar themes across all respondents. Fifthly, the respondents themes were assessed for areas of convergence and divergence in responses.

6.3.1 Families

Participants were asked the broad question: *"What do you think the impact of the study was for the families?"* to explore their experiences and views. Four points were raised: how or when families assist with care; satisfaction and reassurance; communication and relationships, and, death and dying.

6.3.1.1 Assisting with care

In the active unit focus group, the nurses perceived that families enjoyed being involved and wanted to assist with their relative's care. They noted that many already did so for small, simple tasks associated with the personal care for their relatives, that is:

> *"I've noticed a lot that families they will wash their relatives face, they'll brush their hair, personal hygiene things like that." Nurse M, active unit*

That nurses observed that the families were pleased to be able to do something to help, as it gave them a sense of purpose. The participants expressed their experiences watching the families in the following ways:

> *"I think it's given families a role to play. Often when the patient is very sick you can sit there and wait and I'm sure their minds wander…… but it gives them a role to play and a purpose." Clinical nurse educator, active unit*

> "*They feel they are involved." Nursing unit manager, active unit*

The practical activity of passive exercising the patient, served to help the family engage with, and feel connected to, the patient. Being able to help and feel less powerless was valued highly. In the words of a participant, they observed:

> *"The family seemed to enjoy being involved with the care. Not all of them. But most of them liked being able to do things, instead of just sitting by the bedside and not being able to help their loved one, which they have done throughout their whole life and now they are sick and they need their family. They enjoyed that connection that they had with the patient." Nurse B, active unit*

In the Control Unit focus group the families did not enrol to participate in care. However, one participant commented that the wife of an enrolled long-term patient wanted to be involved in passive exercising of her husband. The nurse reported the situation as follows:

> *"She was really excited and she was like can I do this, and I was like yes, if you like go ahead, and she was like stretching his arms." Nurse M, control unit*

There were instances where the task was observed to be challenging for the family. Not surprisingly, families appeared to be stressed by their relatives being in the ICU and completing the exercise task. Nurses recalled this in the following terms:

> *"I did find one family I was watching them do repetitions and they just looked like they had to get through them, I had to get them to slow down and enjoy it. They were going 1, 2, 3, 4, 5." Nurse D, active unit*

This observation highlighted that the families' ability and willingness to participate was not universal. It was influenced by their relationship with the patient, that is:

> *"I had some positive feedback. The family seemed to enjoy being involved with the care. Not all of them. But most of them liked being able to do things, instead of just sitting by the bedside and not being able to help their loved one, which they have done throughout their whole life. They enjoyed that connection that they had with the patient." Nurse A, active unit*

The willingness of involvement was dependent on the pre-existing relationship that the family member had with the patient prior to the admission. Some families were not as comfortable assisting with care for their relative. This was perceived by the nurses to be where there was not that depth of a relationship prior to the admission. A participant noted that:

> *"Obviously it wasn't for everyone. Certain factors that were involved; It depended on their relationship with the patient to start off with" Nurse A, active unit*

Additionally, it was perceived that willingness to participate in care could be related to: the families' cultural background; and the need for the family to maintain the dignity of their family member. In the ICU setting family members may be fearful that participating in care may involve seeing parts of their relative's body that they may not have seen before: such as genitalia and breasts. Previous practice in ICUs has been to nurse patients naked, covered only by sheets, due to the myriad of equipment and lines attached to the patient. Certain cultures, understandably do not accept being exposed to a naked family member of the opposite gender. This was expressed as follows:

"Different cultures were a lot more accepting than others." Nurse D, active unit

"It was important to maintain their (patient) dignity." Nurse E, active unit

For a minority of families, the ICU environment and circumstances for being there was overwhelming. Their response to being invited to assist with the exercises was unexpected. For example, a nurse recalled the comment:

"I had one family say "so you want me to do your job?". But I think they weren't in a good place with the situation, their loved one was very unwell." Nurse W, active unit.

Overall family assisting with care was perceived by the nurses as a positive experience for the family and staff. This led to identifying that there was scope to expand family involvement across the other two ICUs in the service. This is summarised by the nurse manager in this way:

"I think there is huge scope for this. Things like hand massage, a bit of eye care under supervision. Mouth care if it's not contra-indicated from tubes or lines, even pressure area care." Nurse manager

6.3.1.2 Satisfaction and reassurance

It was recognised by the participants that the ICU can be an overwhelming environment for the relatives of the patients. That is, for most people the ICU is a very alien environment due to: the bright lights, loud "alarming" machines, and staff engaged in resuscitating other patients in close proximity to their relative. The nurses perceived that when families assisted with care, not only did it give close proximity to their relative; it meant greater access to the staff looking after them. This translated into the families appearing to be more relaxed and reassured. A nurse recalled their experiences:

"I think because the patients are intubated and all that, the family get quite overwhelmed and quite scared to even sometimes to touch the patient, and in a way it helps them get back to their own way of thinking, this is my father and just because he is sick, I can still touch him, I can still help him out." Nurse H, control unit

It was also observed that because of the study, families started asking what they could do to assist with care rather than waiting to be asked. The nurses saw this as a good thing, as it helped reassure the family member to be involved with the care. This was expressed as follows:

> *"They are always asking, "What can we do?" Sometimes you can see they are worried and the fact that they can be involved. I think if they can do something little like this, they can feel like they are doing something to help their family member." CNE control unit*

This participant talked about giving the family permission to touch. The nurse explained:

> *"This gave families permission to touch their relative; families can feel helpless when surrounded by machinery." Nurse C, active unit*

This was not confined to the active unit, where families undertook the exercises, but also in the control unit, a participant expressed similar sentiments, noting:

> *"ICU is such a frightening environment for so many people that are not medical, it just made them feel, I can touch them, and I'm allowed to move their arm or their leg. It wasn't so frightening for them." Nurse G, control unit*

In the Control Unit, the nurses perceived that being observed by the family when they were performing the exercises was reassuring for the family to see something that was not related to technology and that it encouraged family members to want to be involved. This was reported in the following way:

> *"The family are very happy, they can see the nursing staff are more involved with the patients and passive limb exercises and this improves satisfaction." Nursing unit manager control unit*

> *"It made them feel like they had some power and they were able to enact cares themselves, that made them feel important and satisfied". Nurse G control unit*

Another participant in the active unit witnessed that participation in care had helped a family relax and reassured them. This point was expressed in the following way:

> *"In my experience it was therapeutic for them, it helped them to relax as well and they felt at ease with what they were doing." Nurse J, active unit*

Reassurance of the families was noted as an important care outcome. The details following demonstrated the experiences of participants:

> *"It has definitely helped the families. It's that connection that they've always had with the patient. When they are sick and need their family for them to sit on the sideline. Not being able to provide that care they generally do. Yes they were very accepting of it." Nurse F, active unit*

> *"I found with the family when I was explaining what I was doing, there was a positive response from the family. In that I think they felt something was being done to make their family member more comfortable." Nurse L, control unit*

6.3.1.3 Communication and relationships

All the groups talked about communication, and relationships that developed with the families during their stay in ICU. The exercise activity, and participation of the family had made staff more aware of the families and their needs. The range of comments below highlights the point:

> *"Sometimes during my assessment or at wash time, if the family were there, they were so interested; "Why are you doing that? What does that do?" When I explained to them and they were really interested because it looked so simple, they said "Can we do that?" I felt it made the family interested." Nurse X, control unit*

> *"For me the communication is getting good, because you speak to the family about what you are doing." Nurse K, control unit*

"I think there were times when I was a bedside nurse and the family were there doing the exercises I think it gives you something to talk about." Clinical nurse educator, active unit

"It gives you a conversation point particularly if they are anxious and you are having trouble communicating with them it gives you a common focus to talk about." Nursing unit manager, active unit

"Once you develop a rapport, it's easier for them to talk to you." Nurse B, active unit

As identified by the patient and family demographics section in Chapter 4, and already discussed above, the cohort of patients was multicultural. The nurses identified that even if English was not the first language of the participants, that the family would have a spokesperson. Additionally, having the pictorial information pamphlets assisted with the education process for the passive exercises. A nurse explained:

"The pamphlets came with the pictures, so it was easier. You show them the pictures and point how to do it. They seemed to manage to get it anyway. So it's not really a big problem." Nurse B, active unit

Nurses in all the focus groups expressed that on the whole there were benefits for the family and that it gave the families options when they did not have many. For example:

"It was a positive experience; no one said this is silly. It was like sign me in." Clinical nurse educator, control unit

6.3.1.4 Death and dying

The severity of the patients' illness was discussed in the groups and the impact that this had on the families. One of the participants summarised the subject of death and dying in the ICU with the following:

"Death is a difficult subject for some even when discussing it in the abstract, but it can become even more difficult when the possibility becomes more of a reality. It's

not a subject discussed with any frequency by the general population. Added to which, there is sometimes a distorted and unrealistic expectation of what medical science can achieve. Even when the matter is raised pre-ICU (during the consent for theatre process), many believe or choose to believe that death will not happen to them." Clinical nurse consultant, ICU

6.3.2 Patient

Participants were asked the broad question: *"What do you think the impact of the study was for the patients?"* to explore their experiences and views. Although the patients were central to the study, the conversations about them were limited in the focus groups. This could be due to the fact that the patient was the passive participant in the study. One nurse from the Active Unit commented on a patient who actually requested the exercises when he woke up from being unconscious as it gave him physical relief. This was particularly rewarding feedback for the nurse, realising that what she had been doing was making a difference. She commented that normally her patients were not able to respond. The physical benefits were for the patients and also positively impacted on the wellbeing of the nurses. That is:

"He loved it, he would ask you to do it. He was so stiff and he was so weak, he'd been intubated for weeks and he couldn't do it himself, he really enjoyed having it done." Nurse C, active unit

"To see another benefit for the patient is rewarding for us." Nurse E, active unit

In the control unit there was also feedback from two direct care nurses in relation to the patient. This feedback was via, interactions with the families. Similarly, the nurses felt they were practically making a difference for the patients. The issues were described as follows:

"I found one or two times with the family when I was explaining what I was doing, there was a positive response from the family. In that I think they felt something was being done to make their family member to make them more comfortable." Nurse I, control unit

"You know a little bit of touch can sometime go a long way and it just makes you feel like you are doing something for the person." Nurse G, control unit

"I think from a patient… when you are doing exercises, when you are touching them and you are telling them this is what you are doing, I think it engages them a lot more and they feel like… I am getting stronger today" CNE, control unit

"If you were the patient, in that condition you would want someone massaging your hand even if you were unconscious." CNE, active unit

Participants from the three focus groups commented that in the future passive exercises and the family assisting with care should be available for all patients, unless there were medical contraindications.

6.3.3 Nurses

Participants were asked the broad question: *"What do you think the impact of the study was for the nurses?"* to explore their experiences and views. A particular focus was finding out from the groups, whether the study had been a positive or negative experience for them. Two of the nurses in the control unit stated that some nurses had questioned the beneficence of the exercises, that is:

"There may have been some questions from new staff, around what are the benefits? It was just about educating. Then it was like a light bulb moment… oh, I could see that would work." Nurse J, control unit

"Nursing staff questioned, "Why we are doing it? Will this benefit the patient" So that's where I say it's a study and that's what we are trying to prove whether it's going to benefit or not." Nurse H, control unit

Overall it was perceived that rather than being onerous, the exercises and involving families assisted with the workload and increased staff satisfaction. Several nurses commented on this point:

"It wasn't intrusive, it didn't disturb standard business." Nurse Manager, ICU

"It's not an extra task for us", Nurse M, control unit

"Not difficult it can be melded into work" NUM, ICU

In the active unit it was reported that some staff members were more enthusiastic than others. The difference was reported in this way:

"Some staff were very enthusiastic and positive about it." Nurse D, active unit

Additionally, that exercise program had made the nurses more aware of the family. The explained:

"I am definitely more aware of the family being there; especially when they have been waiting for eight hours or more in the waiting room. I need to get them in as quickly as possible." Nurse A, active unit

The ICU is a very technological environment with machines for ventilation, dialysis, bypass circulation and an EMR. The Control Unit NUM and educator reported that the study had put the focus back on the patient and that this was rewarding for the nurses, that is:

"The nurses their role is more extended from technology, more satisfaction of nursing staff." Nurse Unit Manager, control unit.

"It gave the nursing staff something that was clinical to do, to provide nursing care and interact with the patient on a different level." Clinical nurse educator, control unit

The groups all agreed that this study had given them ideas for other PFCC projects and research. Discussions were about other ways of engaging family in care and other interventions to address ICUAW.

6.4 Conclusion

This chapter has presented the demographics of the three focus groups held with the nurses. Comparing the two units the nurses were of a similar age in both units; however the active

unit nurses were more experienced both as nurses and years nursing in ICU. The third focus group with the nursing leaders showed that they were slightly older and more experienced in the years they had been nursing and years as an ICU nurse. These variations did not appear to have any impact on the different focus groups understanding or ability to discuss the study.

Overall there were positive findings from the focus groups in relation to the families, patients and nurses. There was a sense that families wanted to assist with care in both units. That nurses perceived that when families assisted with care, it gave them proximity to their relative and therefore, reassured them, as well as, facilitating communication with the nurses. There was recognition in the focus groups about the severity of the patients' illnesses and the impact that this had on families when faced with the prospect of their relative's death. Although there was less discussion from the nurses about the patient, it was perceived by them that involving the families would provide reassurance and be comforting to the patient. With respect to the nurses, the perception was that involving families with care, assisted with the workload and increased staff satisfaction.

The limitation of this analysis is that the findings from the three groups were not conducive to separate analysis due to their commonality.

This chapter concludes the presentation of the results; Chapter 7 will critically examine the findings of this study in light of previous research. It will make judgements as to what this research has discovered and how it has added to the body of knowledge, and whether the research questions have been answered.

Chapter 7 Discussion

7.1 Introduction

As stated in the introduction, the research was driven by organisational needs to implement, evaluate and embed PFCC in the ICU. Even though there had been elements of PFCC in the ICUs, there had not been, prior to this research, to the best of the researcher's knowledge, a formal evaluation study conducted and made publicly available. Hence, this study, aimed to address this deficit and, also, commence the process of families participating in care in keeping with the expectations of both the hospital, LHD and NSW Ministry of Health.
In particular, the identified gaps in the knowledge were summed up in the question: if family were to assist with passive exercising of their unconscious relative what would be impact on the families, the nurses, the patients and the healthcare system?

This chapter will critically examine the findings of this study in light of the previous research. It will make judgements as to what this research has discovered and how it has added to the body of knowledge. This chapter is structured as follows. The chapter commences by contextualising the study against previous research that used the CCFNI (section 7.2). The summary of key findings from the study for the families, nurses, patients and healthcare system are then summarised (section 7.3), before each of the research questions are discussed and examined in conjunction with the theoretical framework. The outcomes for the families that were presented in Chapters 4 and 6 are discussed and compared to other studies that had used the CCFNI and NMI (section 7.4). The outcomes for the nurses presented in Chapters 5 and 6 are discussed, and compared to other studies that had used the NSS. The modifications made to the NSS are also discussed as to how they have contributed to the knowledge (section 7.5). The clinical and healthcare outcomes in Chapter 4 are presented together as there is some synergy with the instruments used for this part of the research (section 7.6). The analysis considering the theoretical framework is presented (section 7.7) before the chapter concludes by summarising the findings from this thesis (section 7.8).

7.2 Study contextualised with previous research

As stated in the introduction to this chapter, to the best of the researcher's knowledge there had been no previous PFCC studies in the ICUs at the study site. Therefore, prior to this study the demographics of the patients and their families in the units were not well understood. What is known of the NSW community is that it is diverse. In the 2016 Australian Census there were over 7.48 million people living in NSW; of these, 2.9 % identified as Aboriginal and/or Torres Strait Islander, nearly 35% were born overseas and approximately one in four people spoke a language other than English at home. Males made up 49.3 % of the population and over 33% of the population were greater than 50 years of age (ABS 2016).

The patient and family demographics from this study were compared against other national and international PFCC studies (Table 7.1) that had used the CCFNI in either the original 42-item, or the modified versions (Azoulay et al. 2003; Bailey et al. 2009; Baning 2012; Burr 1998; Gentry et al. 2014; Kinrade, Jackson & Tomnay 2010; Leske 1991; Maxwell, Stuenkel & Saylor 2007; Molter 1979; O'Neill-Norris & Grove 1986; Obringer, Hilgenberg & Booker 2012).

Table 7. 1: Comparative studies that used the CCFNI

Author Year	Setting	Purpose of the study	Instrument	Sample size (n)	Findings
Molter (1979)	2 teaching hospitals USA	Ascertain needs of families of critically ill patients and whether needs met and who is helping to meet the needs	Original 45 need statements CCFNI	Relatives 40 (25% female 23% wives)	Highest ranked needs on CCFNI were from the assurance domain and included: To feel there was hope To feel that hospital personnel cared about the patient Adequate and honest information Ranked low
O'Neill-Norris and Grove (1986)	6 ICUs in a major medical centre USA	Investigation of psychosocial most and least important needs as perceived by family compared to nurses	30 item CCFNI	Relatives 20 (70% female)	Highest ranked needs on CCFNI were from the assurance domain and included: To feel there was hope To have questions answered honestly Ranked low on CCFNI was: To talk about the possibility

Author Year	Setting	Purpose of the study	Instrument	Sample size (n)	Findings
					of the patient's death To talk about feelings To have visiting hours changed
				Nurses 20	Nurses' perception of family needs varied to the families' perception of need. They ranked low: To help with the patient's physical care To talk about the possibility of the patient's death
Leske (1991)	14 states USA	To examine the internal consistency, reliability and construct validity of the CCFNI	42 item CCFNI	Relatives 677 (71% female 39% spouses)	69% patients male The research supports the CCFNI has sufficient validity and reliability for family needs in various populations, and a measure of need importance as a result of nursing intervention.
Burr (1998)	4 ICUs in 4 major teaching hospitals Sydney Australia	Triangulation of CCFNI compared to structured interviews with family members to determine the degree of confirmation.	43 item CCFNI	Relatives 105 Combined CCFNI and interviews (72% female 68% wives)	Highest ranked needs on the CCFNI were from the assurance domain and included: To feel that hospital personnel cared about the patient To be assured that the patient is receiving the best possible care Ranked low on CCFNI was: To help with the patient's physical care Items relating to personal comfort of family
			Interviews	Relatives 26	Two major needs emerged from the interviews that are not represented on the CCFNI: the need of family members to provide reassurance and support to the patient; and their need to protect (others as well as the patient).
			43 item CCFNI	Nurses 90	Not reported
			Interviews	24	
Azoulay et al.	1184 beds in 78 ICU	To investigate the	30 item CCFNI	Relatives 544	221/62% of patients male Mean age 61 years

Author Year	Setting	Purpose of the study	Instrument	Sample size (n)	Findings
(2003)	across France	opinions and experience of ICU caregivers and family members about involvement of families in the care of ICU patients	and interview		
				Caregivers 2754	Most ICU caregivers are willing to invite family members to participate in patient care, but most family members would decline.
Maxwell, et al (2007)	16 bed CCU in a 375 bed community hospital USA	To explore differences in perception of the needs of family members of critically ill patients and RNs perceptions and the extents to which these needs were met	30 item CCFNI	Relatives 20	Highest ranked needs on the CCFNI were from assurance domain and included: To have questions answered honestly To know the prognosis To talk with the nurse each day To know how the patient is being treated. Families ranked low: To talk about feelings To help with the patient's physical care Family needs were met in: To see the patient frequently To talk with the nurse each day To have questions answered honestly To be assured that the best possible care was being given to the patient 10/62% of patients male Mean age 60 years
				30 nurses	There was difference in perception between the families and nurses for nine items. Nurses ranked all items less important than the family and included: To know the prognosis. To talk with the nurse each day To know why things were being done for the patient To be called at home about changes in the patient's condition
Bailey et al (2009)	22 bed ICU in a 659 bed teaching hospital Montreal Canada	Supporting families in the ICU: A descriptive correlational study of informational support,	Modified CCFNI	Relatives 29/39 (74%) (83% female 34.5 %	Highest ranked needs on the CCFNI were from assurance domain and included: To have questions answered honestly To have explanations given

Author Year	Setting	Purpose of the study	Instrument	Sample size (n)	Findings
		anxiety, and satisfaction with care		wives) 68% of patients were female	that are understandable Informational support improves family satisfaction by reducing anxiety. A significant positive correlation was found between informational support and satisfaction with care
Kinrade, et al. (2010)	ICU regional Victoria, Australia	To explore the needs of relatives whose family member is unexpectedly admitted to an ICU and compare ranked need statements between family and nurses	42 item CCFNI	Relatives 25 (88% female)	Highest ranked needs on the CCFNI were from assurance domain and included: To have questions answered honestly To feel that hospital personnel care about the patient To know specific facts concerning the patient's prognosis
				ICU nurses 33/48 69%	Highest ranked needs on the CCFNI were from assurance domain and included: To have questions answered honestly To be assured that the best possible care is being given to the patient To feel that hospital personnel cared about the patient To have explanations given that are understandable Ranked low on the CCFNI was: To help with the patient's physical care Comparative analysis of the data revealed that there were minor differences identified in the rank order of the need statements listed in the CCFNI amongst nurses and family members. A comparison with previous studies also identified minor differences in both the rank order of individual need statements and the five factor analysis categories previously established.
Garrouste-Orgeas et al. (2010)	10 bed ICU in a 460-bed tertiary-care hospital in Paris,	The aims of the study were to assess opinions of caregivers, families, and	CCFNI Follow up phone calls to patients	101 patient and family pairs	Families and ICU staff were very supportive of family participation in care. Most patients were also favourable to care by family

Author Year	Setting	Purpose of the study	Instrument	Sample size (n)	Findings
	France.	patients about involvement of families in the care of ICU patients; to evaluate the prevalence of symptoms of anxiety and depression in family members; and to measure family satisfaction with care.		ICU Staff 21 nurses 7 assistant nurses 17 physician	members. Only 14% of family members provided care spontaneously.
Baning (2012)	ICU 377 bed not for profit tertiary hospital south-west USA	Evaluation of outcomes of a comprehensive patient and family centred care program for families of ICU patients	30 item CCFNI	Relatives 22	<u>Baseline</u> Highest ranked needs on the CCFNI were from assurance domain and included: To know how the patient was being treated To know why things were done for the patient To be assured that the best possible care was being given to the patient To have questions answered honestly
				Relatives 22	<u>Post intervention</u> Highest ranked needs on the CCFNI were from assurance domain and included: To know the prognosis To have questions answered honestly To know specific facts about the patient's condition
				Nurses 39	Perceptions between the nurses and families differed in relation to family needs
				Nurses 46	Further study is needed to determine the effectiveness of the CCFNI/NMI in measuring outcomes before and after a PFCC intervention.
Obringer, Hilgenberg Booker (2012)	22 bed ICU Not for profit hospital USA	To examine current perceptions of family needs	45 item CCFNI	Relatives 45 (67% female) (36% spouse)	Highest ranked needs on the CCFNI were from assurance domain and included: To be assured that the best care possible is being given to the patient To know the expected outcome To be called at home about changes in the patient's condition

Author Year	Setting	Purpose of the study	Instrument	Sample size (n)	Findings
					Findings were consistent with earlier studies identifying assurance as a very important need.
Gentry et. al (2014)	8-16 medical surgical ICU USA	A study to evaluate the needs of family members of critically ill patients in the ICU	45 item	20 (75% female) (20% spouse)	Highest ranked needs on the CCFNI were from assurance domain and included: To have questions answered honestly To talk with the doctor every day To know the expected outcome To be assured that the best care possible is being given to the patient Findings support studying family needs in the ICU, and support the CCFNI as a valid and reliable instrument.
Mitchell et al. 2019	A tertiary intensive care unit Australia.	A mixed method study to identify the needs of families of trauma patients in the intensive care unit and to assess nurses' perceptions of those needs.	45 item	50 families of trauma patients 53 families of general ICU patients 111 nurses	The study identified that families of trauma patients have different needs to families of general patients and the nurses rated the needs of the families of trauma patients as less important than the families rated their own needs.
Dixon (2019)	2 general medical and surgical ICUs in a public hospital Sydney, Australia	A study to assess the impact on families, patients, nurses and the healthcare system of family-assisted passive exercises of unconscious patients in ICU.	30 item CCFNI and NMI	19 families completed CCFNI and NMI	The results of the CCFNI and NMI presented in Chapter 4, showed that Pre-test the CCFNI showed the items from the assurance domain were ranked the highest in both units. Post-test the NMI for the active unit showed, six of the top ten items ranked as most important on the CCFNI were ranked in the top 10 most frequently met as measured by the NMI. All items were from proximity and assurance domains. Items not met were *to know the prognosis* and *to talk about the possibility of the patient's death*. Ranked low were *to feel there was hope* and *to be called at home about a change in the patient's condition.* Post-test for the Control Unit, four items were not

Author Year	Setting	Purpose of the study	Instrument	Sample size (n)	Findings
					met; *to be called at home about changes in the patient's condition, to be told about transfer plans when they are being made, explanation of the environment* and *to be told about other people that could help with problems.* Ranked low were *to know the prognosis* and *to talk about the possibility of the patient's death.*
				100 nurses pre-test and 80 nurses post-test	In the active unit post-test, the mean scores of the nurses, for all the domains showed a positive improvement, with a statistical improvement (P=.01) in the proximity domain. This demonstrated that post-test the perception of families' needs between the families and the nurses were more aligned. This was not matched in the control unit. Pre- and post-test the nurses did not score the proximity domain as high as the family.The means of the comfort and assurance domains decreased post-test. The results showed that there was a disparity between the families and the nurses in relation to perceptions of family needs, pre- to post-test.

The data showed that at the study site: the majority (84%) of the patients were male; the mean age of the patient was 56 years and the majority (90%) of the family members were female. These results were comparable to the other studies which recorded: the majority of patients as male (Azoulay et al. 2003; Maxwell, Stuenkel & Saylor 2007; Mitchell et al. 2019); similar mean ages (Azoulay et al. 2003; Maxwell, Stuenkel & Saylor 2007) and a majority of the family members as female (Auerbach et al. 2005; Bailey et al. 2009; Gentry et al. 2014; Kinrade, Jackson & Tomnay 2010; Leske 1991; Maxwell, Stuenkel & Saylor 2007; Mitchell et al. 2019; O'Neill-Norris & Grove 1986; Obringer, Hilgenberg & Booker 2012). Further examination of the family members at the study site, revealed that over half of them

were wives of the patient; this is also comparable to other studies (Burr 1998; Mitchell et al. 2019).

Factoring the age of these patients and the relationship with the family members, a large proportion who were wives, and that the admissions were unplanned, identifies there are different psychosocial aspects that need to be considered for these patients and their families. For example, there may be loss of earnings and reversal of roles for this cohort of patients and their families (Griffiths et al. 2013; Mitchell et al. 2019; Molter 1979). This may not always be obvious to the nurses looking after the patient. That is, as to the role that the patient fills in the family (Cannon 2011; Olding et al. 2016). It could also be suggested that there may be more commitment to a spouse from a partner than, possibly, other family members.

It has also been inferred that gender and age of the family member may affect their needs (Griffiths et al. 2013; Molter 1979). The other factor to note is the higher commitment shown by female relatives. In this study, besides the patient's wives, their mothers, daughters and sisters, made up 32% of the participants. Notwithstanding, that the ICU arguably, admits equal numbers of male and female patients, a question that came out of this study that would warrant further research is: whether there is a gender bias of patient's visitors, carers or others assisting with care? This was an incidental finding from the studies examined, but this does not appear to have been fully examined or researched.

Australia is a multicultural society, although 58% of the patients identified their ethnicity as Australian and of these, 10% identified as Indigenous Australian, the remaining 42%, were from other countries. Even though the information pamphlets were in English, this did not appear to be a barrier for people for whom English was not their first language. There were visual aids in the pamphlets and the families usually had a support person that helped address any communication issues. These findings were supported by the discussions in the focus groups.

As previously identified in the setting sections of Chapters 1 and 3, the study site hospital provides tertiary and quaternary services for patients from across NSW, interstate and internationally. This was confirmed by the profile of the cohort of patients with only 21% coming from the District catchment. The usual flow of patients into the ICU is 70% from the District. This information was collected as it was thought that families that were not local

may not be available to take part in the study; however, the reverse was the case. This was thought to be due to the fact that if the family member came to Sydney to be with their relative, they were actually more available during the day, as they did not have work commitments or their home to go back to. It is a reality in Australia, that patients have to come from rural and regional areas for tertiary specialist treatments (Mitchell et al. 2019), and their families accept being away from home for as long as necessary (Burr 1998; Coyer 2004).

Additionally, it is worth noting that patients being transferred for tertiary and quaternary services are often the sickest cohort within the ICU. This fact could explain the high mortality rate in this study. This should be considered when designing future studies. While the ICUs at the study site have a varied case-mix of patients, the metrics set for the inclusion and exclusion criteria, tended to lead to the cohorts of patients with either respiratory or liver disease. These patients were often the sickest cohort within the units and potential patients were sometimes palliated before they were even enrolled, and of those enrolled, as mentioned, a larger proportion than expected died. Post-test this was identified as a limitation to the study.

The sample size of the families and patients was small and therefore, this has implications for the significance and generalisability of the findings. It is acknowledged that a multi-centre study would have given a greater sample size (Azoulay et al. 2003; Cuthbertson et al. 2010). However, even with this small sample size, there were similar findings with other studies both nationally and internationally in relation to the sample size and the demographics (Kinrade, Jackson & Tomnay 2010; Maxwell, Stuenkel & Saylor 2007; Mitchell et al. 2019; O'Neill-Norris & Grove 1986). Particularly, in relation to: the age and gender of the patient (middle aged men) (Azoulay et al. 2003: Maxwell, Stuenkel & Saylor 2007) and the gender of the care giver (female) (Auerbach et al. 2005; Bailey et al. 2009; Gentry et al. 2014; Kinrade, Jackson & Tomnay 2010; Leske 1991; Maxwell, Stuenkel & Saylor 2007; Mitchell et al. 2019; O'Neill-Norris & Grove 1986; Obringer, Hilgenberg & Booker 2012), and the social implications that this can have (Griffiths et al. 2013; Molter 1979).

The demographic information gathered from this study, has given a better understanding of the patient and family cohorts in the active and control units. In that, the demographics of: the enrolled patients and their families, those lost to follow-up and the final sample size in both

units (Chapter 4), were comparable for: the patients' age, gender and ethnicity; and, gender and relationship of the patients' family member. Variance, was with the presenting medical condition of the enrolled patients, with the active unit having a higher percentage of patients with respiratory illnesses, whereas, the control unit had more patients with liver disease. Overall, in this regard, however, there was no notable difference in the demographics between the active and control units, demonstrating that the units were suitable for a comparative study. This comparison, of the patient and family demographics between the active and control units was unique to this study.

7.3 Summary of key findings

The premise of this study was the need for further empirical research on PFCC in the ICU. It sought to establish whether family assisted passive exercises of unconscious patients could improve outcomes for the families, nurses, patients and healthcare system. Using the purpose designed PFCC, theoretical framework for family assisted passive exercising in ICU (Donabedian 1988; McCormack & McCance 2006; Picker Institute 2008), the outcomes were measured by examining whether: family satisfaction was improved by meeting their needs; nurses' satisfaction was improved by reducing workplace stressors; patient outcomes were improved by reducing muscle wasting and weakness, ventilator hours, length of stay and mortality; and healthcare system efficiencies improved by reducing patient ventilator hours and length of stay. For ease of reference, Table 7.2 summarises the research study, including: the study aims that led to the research questions and helped inform the theoretical framework; participants; instruments; key findings; and the corresponding chapter within the thesis.

Table 7. 2: Summary of research study

Study aim	Research question	Participants	Instrument	Key Findings	Corresponding chapter
The study aim was to determine if family assisted passive exercises of unconscious patients could improve	Can family assisted passive exercises on unconscious patients in an intensive care unit, achieve better outcomes for	Families and nurses	CCFNI	Disparity between the family and nurses of both the active and control units pre-test in relation to perception of family needs. Post-test there was	Chapter 4: Section 4.5.1

Study aim	Research question	Participants	Instrument	Key Findings	Corresponding chapter
outcomes for the families, nurses, patients and healthcare system.	families?			improvement in the active unit not matched in the control unit.	
		Nurses	CCFNI	The comparison of the nurse pre- and post-test showed improvement of perception of family needs in the active unit not matched in the control unit.	Chapter 4: Section 4.5.2
		Families	CCFNI NMI	In the active unit there was improvement in needs being met. In the control unit, three domains of need were not met.	Chapter 4: Section 4.6
		Families	FFS	The distribution of how likely the families were to recommend the service to friends and family was the same across both units.	Chapter 4: Section 4.7
		Nurses	Focus groups	The nurses reported positive findings in regards to families assisting with care; family satisfaction and reassurance and improvement in communication and relationships between the families and nurses.	Chapter 6
	Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for nurses?	Nurses	mNSS	There were statistically significant differences in the active unit and improvements in the mean scores of the mNSS, not matched in the control unit. The modifications to the instrument were tested using Cronbach's alpha. The results showed a satisfactory level of consistency: pre- and post-test.	Chapter 5

Study aim	Research question	Participants	Instrument	Key Findings	Corresponding chapter
		Nurses	Focus Groups	The groups reported that generally the study had been a positive experience for the nurses and that it had given them ideas for further PFCC research.	Chapter 6
	Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for patients?	Patient	Ultrasound measurement tape measure FAPEI	The distribution of change was the same across both units and all patients lost muscle mass. The distribution of ventilator hours, LOS in ICU and the hospital was the same across all groups. Mortality for the patients was greater than the ICU average.	Chapter 4: Section 4.8.1
	Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for the healthcare system?	Patient	FAPEI	The distribution of ventilator hours, LOS in ICU and the hospital was the same across all groups.	Chapter 4. Section 4.8.2

7.4 Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for families?

This question was tested using the CCFNI, NMI and FSS instruments and the focus groups held with the nurses. These instruments align with the PFCC principles of the chosen theoretical framework, in particular around: emotional support, partnering with families, physical comfort, information and education, respect for patient preference, coordination and integration of care (ACSQHC 2017; Picker Institute 2008). This section will discuss the findings in relation to the families and will make a comparison to other studies that used versions of the CCFNI and NMI, as outlined in Table 7.2. It will: validate any existing

knowledge; identify where this study has generated any new knowledge and identify areas for future research and service improvement.

7.4.1 Identified needs and needs met

As discussed in Chapter 2, family needs of ICU families have been studied extensively since Molter's seminal work in 1979. However when searching the literature there were limited studies that explored interventions assisting with meeting family needs (Baning 2012; Goldfarb et al. 2017; Kean & Mitchell 2014; Mackie, Mithcell & Marshall 2016; Mitchell et al. 2009; Nolen & Warren 2014) and no studies could be found with families assisting with passive exercises.

The study used the unique theoretical framework of family assisted passive exercising in ICU that was presented in Chapter 2. This framework incorporated the CCFNI, NMI, FFS instruments and the focus groups. The aim was to demonstrate that the family assisted passive exercising of the ICU patient, using the SPO model (Donabedian 1988) could improve the outcomes for the families by meeting their needs in keeping with PFCC principles (McCormack & McCance 2006; Picker Institute 2008). It was anticipated that a PFCC study could better align the nurses' to families' perceptions of needs and therefore improve satisfaction for both groups. This is important as it has been reported that family members experience high anxiety and disorganisation in response to critical illness, and nurses must know the needs of the families to provide holistic care to the patient (Nolen & Warren 2014; Obringer, Hilgenberg & Booker 2012). As discussed in section 7.2, the patients and their families were from many cultures, and it has been noted that there is a widespread need for assurance across a variety of cultures and that nurses are instrumental in ensuring this assurance (Obringer, Hilgenberg & Booker 2012).

7.4.1.1 CCFNI

The CCFNI was completed by the families pre-test and by the nurses pre- and post-test. The individual ranking of questions presented in Chapter 4, showed that the families of the active and control units, as in previous studies, ranked *to have questions answered honestly* (Maxwell, Stuenkel & Saylor 2007) as one of the highest needs, along with, *to be assured*

that the best possible care was being given to the patient (Baning, 2010; Burr, 1998; Kinrade, Jackson & Tomnay, 2010) and *to feel there was hope* (Baning, 2012; Kinrade, Jackson & Tomnay 2010; Molter, 1979: O'Neill-Norris & Grove 1986). These items were from the assurance domain.

The least important needs identified by the families on the CCFNI were: *to have an explanation of the environment before going in*; *to talk about feelings* and *to have a telephone in the waiting room.* Previous studies identified that families accorded low priority to their personal needs compared to patient related needs (Burr 1998;Kinrade, Jackson & Tomnay 2010; Maxwell, Stuenkel & Saylor 2007; Molter 1979; O'Neill-Norris & Grove 1986) and these findings verify this. However, it is questionable that the telephone in the waiting room question is still relevant in a world with mobile phones. The need for phone chargers is a more pressing need and at the study site these have been installed to address this need.

Families compared to nurses pre-test

The analysis of the results of the CCFNI completed by the families pre-test compared with the respective nurses pre-test revealed that the nurses and families did not differ much in their perception of the importance of the domains of support and comfort. However, they differed a great deal in the domains of proximity, information and assurance, with the families from both units rating the importance of these domains higher than the respective nurses. These results were consistent with the previous studies, shown in Table 7.2 that demonstrated significant differences in perception of needs and needs met between nurses and family members (Baning 2012; Kinrade, Jackson & Tomnay 2010; Maxwell, Stuenkel & Saylor 2007; Mitchell et al. 2019; O'Neill-Norris & Grove 1986).

Families compared to nurses post-test

The analysis of the results of the CCFNI completed by the families pre-test compared to the respective nurses post-test, showed improvement in perception of family need for the nurses of the active unit. In particular, the domain of proximity showed a positive, significant change. However, for the nurses of the control unit the CCFNI ratings remained static and, in the case of the comfort and assurance domains receded at post-test. This indicates that the active unit nurses were more aligned to the families' needs, after the intervention of family

assisted passive exercising, but that there was still disparity in the control unit between the families and nurses.

The comparison of family perception of needs to nurses' perception of family needs is not widely researched and is still worth examining to ascertain differences between the two groups, so that service improvements can be made (Hinkle, Fitzpatrick & Oskrochi 2009).

Comparison of nursing seniority

The demographics of the nurses were collected for years of nursing and years of nursing in ICU, as there was an assumption that the more experienced nurses may be more aligned to the perspective of family needs (Kean & Mitchell 2014). Previous studies have suggested that years of nursing experience do not necessarily correlate to greater understanding of family needs (Burr 1998; Davidson 2009; Kinrade, Jackson & Tomnay 2010). This appeared to be the case at the study site with the most junior nurses of both the active and the control units ranking higher than more senior nurses pre-test. In particular in relation to the highest identified need of the family *to have questions answered honestly*. This difference was not noted post-test.

Intuitively, it can be suggested that the direct care nurse that has more contact with the patients and relatives, will have formed a closer relationship with them and therefore be more attuned to their needs. It could be argued that the nurses that are managing the units do not require the same skill set as the bedside nurse and that possibly they have become inured to the needs of ICU families. However, the bedside nurse will look to their more senior colleagues for support and advice in regards to patient care and their interaction with patients and their families. Therefore, it is important that all nurses are aware and facilitate the needs of families. A recommendation from this study is that the more senior nurses still engage regularly in direct care nursing. This will help them with maintaining both their clinical and communication skills, which will benefit the patients, the relatives and themselves. Additionally, this action would provide role modelling for newer and less experienced staff.

7.4.1.2 CCFNI compared to NMI

As well as comparing the results of the CCFNI completed by the families and nurses, post-test the results of the CCFNI were compared to the NMI completed by the families. This was

to determine whether the families perceived that their needs had been met. In both the active and control units, the families indicated that their needs were met in four areas: *to talk to a nurse each day; to see the patient frequently; to be assured that the best possible care was being given to the patient; and to have questions answered honestly.* These needs met corresponded closely to those identified by Maxwell, Stuenkel and Saylor (2007), which was somewhat surprising given that their study setting was quite different. In that, it took place in a coronary care unit, in a small community hospital in the north of California, USA. Although the patients were classified as critically unwell, the study did not indicate that they were unconscious or being mechanically ventilated. It was also unclear at what stage of the patient journey the family completed the NMI.

The results for this study are reassuring as the patients had a dedicated nurse for each shift while they were receiving mechanical ventilation and the findings in relation to the communication with the nurses and having questions answered honestly reflects this. To see the patient frequently could be attributed to the fact that the ICUs has implemented an open visitation policy (Wong et al. 2015) and the families are recognising that they could see their relative as suited their circumstances.

Two items that were ranked low by the families of the active unit on the CCFNI that showed a significant improvement on the NMI were: *to talk about feelings* and *to have directions of what to do at the bedside*. This could be directly attributed to the engagement of the families with the direct care nurses with the intervention. As a result of these findings the involvement of family with care has been implemented across all four units at the study site. This is being driven by a local patient and family centred care committee comprising of direct care nurses, managers and educators. To date they have developed purpose designed instruction pamphlets and training for care that involves; hair brushing, hand massage, eye care and mouth care.

7.4.2 Needs not met

Previous studies have identified - *to be called at home about changes in the patient's condition*, as one of the top needs for families (Burr 1998; Mitchell et al. 2019). This item comes from the proximity domain and addresses the fundamental needs of family members to

be there for their relative (Leske 1998; Obringer, Hilgenberg & Booker 2012). At the study site this was ranked the second highest need by both cohorts of families on the CCFNI but on the NMI the mean scores indicated that the needs were not met. This need, not being met and therefore, lack of perception of this family need by nurses has been identified in previous studies (Mitchell et al. 2019; O'Neill-Norris & Grove 1986) and continues to be a challenge for ICUs.

On reflection, the reasons for these findings are probably multi-factorial, but could be speculated to stem primarily from issues in communication. Although previous studies have identified some nurses as not as caring as their colleagues (Donnelly & Psirides 2015), it could be contended that there are other issues that account for this failure. Such as: not wanting to disturb an exhausted relative at night; getting caught up with looking after the patient; poor handover between shifts; inexperienced nurses not feeling comfortable to convey distressing news to a relative; it may have been due to a rapid deterioration in the condition of seriously unwell patients, that we now know this cohort comprised of. Alternatively it could be considered a mismatch of expectations. This has now been identified as an area for service improvement at the study site. An admission process that will address this deficit is being developed by the ICU nurses to help meet this need. This will require ongoing education of the process for current staff and will become part of the orientation of new nurses to the ICUs. Once the process has been implemented families will be resurveyed to make sure that this deficit has been addressed.

The second need not met in both units was from the support domain - *to talk about the possibility of the patient's death.* Although this need was not ranked as high pre-test on the CCFNI as were other needs, family perception changed during the ICU stay. It can be argued that this finding can be attributed to post-ICU families have more time to reflect on their experience, once the focus on survival changes to the patient having survived or not (Efstathiou & Clifford 2011). In this study the findings could also be attributed to how sick these cohorts of patients were and the fact that they were more at risk of dying. This was a fact that the family members did not consider given the median age of these patients was below the age at which death could be reasonably anticipated. However, as presented in Chapter 4, Table 4.31, 37% of the patients in this study died. Bearing this in mind and the fact that all the admissions were unplanned, patients may not have had advanced care directives or expressed their views to family members on the extent of treatment that they

would agree to. Families may have been faced with the difficult decision around end-of-life care and whether to continue with treatment that may have been futile with a low probability of survival and high probability of severely impaired cognitive function (Cook & Rocker 2014). This would be an added stressor for the families impacting on their perception of this need.

Another factor to consider in why this need was not met, is that some nursing and medical staff may feel uncomfortable having conversations with the family around death and dying and end-of-life care (Brooks, Manias & Nicholson 2017; Efstathiou & Clifford 2011; O'Neill-Norris & Grove 1986; Shorter & Stayt 2010; Stayt 2009). This is not unique to the study site. It has been noted that: critical care clinicians are not necessarily trained or skilled in facing end-of-life care as the focus is on treatments to prevent death (Brooks, Manias & Nicholson 2017; Buckley & Andrews 2011; Efstathiou & Clifford 2011; Kentish-Barnes, Chevret & Azoulay 2018; Trankle 2014); and, that there may be little preparation time when the decision is made to no longer actively treat a patient and to move to palliation (Brooks, Manias & Nicholson 2017; Efstathiou & Clifford 2011). As discussed in section 7.2 of this chapter, 79% of the patients were not from the District. This would indicate that the families may not be familiar with the hospital or the clinicians. Given the nature of the patients' illnesses, death could occur before a rapport had developed between the families and clinicians (Cook & Rocker 2014) impacting on communication.

End-of-life conversations have been identified as an area for service improvement, given that nurses identified the items on the mNSS in relation to death and dying as being stressful. This has given the impetus for two initiatives, to address this identified deficit, which includes: a multi-disciplinary end-of-life working party; and a communication training program called Hospital End of Life Planning (HELP).

The end-of-life working party comprises of nurses, doctors, social workers and consumers and meets monthly. The purpose of the group is to: revise and update the end-of-life guidelines for the ICUs; and improve staff confidence in communication with grieving relatives. Other developments from this group are the ability for families to have keepsakes such as hand prints or locks of hair of their family member and the sending of condolence cards to families following the bereavement.

The HELP communication training program is also multi-disciplinary and is being developed by ICU nursing, medical and social work staff. It is scenario based training using actors playing bereaved relatives. It is anticipated that this will commence in late 2019 and will be an ongoing training program for ICU nursing and medical staff.

Even though the CCFNI instrument was developed nearly 40 years ago these findings demonstrate that it is still valid in the current ICU environment. In spite of the many changes in healthcare over the years, families' needs remain consistent and dealing with dying and death remains a significant challenge, and source of stress, for health professionals.

7.4.3 Family Feedback Survey

The FFS instrument was used as a measure for families to rate their experience in the ICU. The overall responses as presented in Chapter 4 were positive. As discussed in Chapter 3, this tool was based on the NHS Family and Friends Test, which had been well received when the study was being developed. More recently it has been suggested that an open comments section could provide more actionable feedback (Robert, Cornwell & Black 2018). This statement is supported by the limited information gathered through this instrument. It could also be argued that there was some participant bias, as the families were engaged in the study (McCambridge, Witton & Elbourne 2014). The family responses were more likely to be positive, than if a random family member who had not been part of the study had been approached to give their opinion on the service.

7.4.4 Focus groups

The nursing focus groups were, as presented in the study design in Chapter 3, the smaller part of the study. They were held to: triangulate the data from the quantitative instruments; and obtain a greater understanding of the nurses' perspective on PFCC. The study used an explanatory design to investigate a significant practice problem in the ICU context.
At the time of commencing the study little was known about ICUAW and its relationship with patient and family centred care. Hence, the exploration into the topic and the use of focus groups to gather more detailed information from the nursing perspective.

All of the participants of the focus groups were positive in their responses to the study and the benefits that it had provided for the families. Three points were identified from the discussions in relation to the families: how or when families assist with care; satisfaction and reassurance; and, communication and relationships. These themes correlated to the PFCC principles of the theoretical framework (ACSQHC 2017; McCormack & McCance 2006; Picker Institute 2008) .

The overall view of the participants was that families wanted to and, indeed, enjoyed being involved with their relatives care. That families were reassured by assisting with the patient's care, as it gave them greater access and proximity to the patient. This finding reported by the nurses confirms and validates the NMI findings for the families of the active unit.
All the participants agreed that the study had made them more aware of the families and that it had facilitated discussions and improved communication with family members and the nurses. This finding from the study supports that the interpersonal contact that the nurses had with the families helped meet the families' informational needs (Auerbach et al. 2005; Bailey et al. 2009; Jacob et al. 2016; Molter 1979). Notwithstanding that this has been supported in previous studies, as discussed in Chapter 1, there was a need to implement, evaluate and embed PFCC in the intensive care at the study site. This required a study, such as this one to identify the needs of families and for the nurses to appreciate the benefits of family assisting with care in keeping with the National Safety and Health Service, Standard 2, *Partnering with Consumers* (ACQSHC 2017).

This was noted as a paradigm shift for the ICU nurses to focus more on the emotional (Picker Institute 2008) and psychological needs of the family as too often in the ICU the focus can be on the technology and physiological aspects (Burr, 1998; Wong et al. 2015). There were discussions around the machinery in ICU and the fact that this can be intimidating for relatives of patients, but assisting with the exercises, gave families permission to touch (Adams et al. 2014; Burr 1998).

The groups all agreed that this study had given them ideas for other PFCC projects and that there was scope to expand family involvement with care, across the other two units in the intensive care service. It was beneficial to hear the feedback from the nurses as the surveys did not give this level of detail. These findings validated the elements of the theoretical framework that drew on Picker's principles of PFCC (Picker Institute 2008) and McCormack

and McCances' person-centred nursing (McCormack & McCance 2006) and supported Standard 2, Partnering with Consumers (ACSQHC 2017).

As discussed in Chapter 3, one of the limitations to this study was that families were not interviewed as part of the qualitative data collection. When the study was being planned, in 2015, it was considered that focus groups or interviews might be too intrusive on families at a time of extremis. Since finishing the study, and further reviewing the literature, it has been noted that families, even when bereaved have reported that being involved with research can be a positive experience (Buckley et al. 2015; Kentish-Barnes et al. 2015). Hence, there is a need for research that can promote greater engagnement with families in clinical practice in such situations.

It has also been noted that PFCC is often driven by what nurses' perceive families want and as this and previous research has demonstrated, this does not always coincide with what families want and need (O'Neill-Norris & Grove 1986). There is also the power imbalance that occurs between the family and caregiver. Families may want to be involved with care but will not necessarily ask (Kean & Mitchell 2014). Indeed, in this study it was observed that because of the study, families started asking what they could do to assist with care, rather than waiting to be asked. The nurses saw this as a good thing, as it helped reassure the family member to be involved with the care and that it gave families options when they did not have many.

7.5 Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for nurses?

This question was tested using the mNSS and the focus groups. These instruments aligned to the outcome component of the SPO model that made up part of, the theoretical framework for family assisted passive exercising in ICU. This section will discuss the findings from the study in relation to the nurses. It will make a comparison to other studies that used versions of the NSS. It will: expand on the demographics of the nurses; validate any existing knowledge; identify where this study has generated any new knowledge particularly in relation to the modifications made to the instrument; and, identify areas for future research and service improvement.

There was an excellent response rate to the surveys distributed to the nurses. This was attributed to the mode of distribution, which was paper based and delivered by hand pre- and post-test. This mode of distribution has been reported to generate higher response rates than electronic surveys (Nulty 2008; Stellefson et al. 2018). It is important to get a good response rate to surveys, to ensure that it is representative of the study sample and reduces non-response bias (Fincham 2008; Jones et al. 2019).

7.5.1 Nurses demographics

As discussed in Chapter 5, the demographics of years of nursing and ICU nursing experience were collected to assess the skill mix of the nurses in both the active and control units. This information was collected to: determine if the units were suitable for a comparative study; assess how the level of seniority impacted on stress levels; and whether the intervention would have the same effect on stress levels for each cohort of nurses (Kean & Mitchell 2014; McCarthy, Power & Greiner 2010).

The results showed that there was minimal difference in skill mix, between the nurses from the active and the control units. In relation to years of nursing and years nursing in ICU and there was minimal change from pre- to post-test in relation to this skill mix. This meant that the units were suitable for a comparative study.

7.5.2 Nursing stress

The mNSS was used to assess whether an intervention, in this case family assisted passive exercising, would improve the stress levels and satisfaction of ICU nurses. The original NSS developed by Gray-Toft and Anderson (1981) was later modified to suit different settings (French et al. 2000; Gray-Toft & Anderson 1985; Pathak, Chakraborty & Mukhopadhyay, 2013). The modifications were in recognition that different environments and clinical settings may have different stressors. For this study to gather more information pertinent to this study, modifications were made to the instrument adding four extra questions as an eighth factor. As presented in Chapter 3, the study specific questions were tested for internal consistency using Cronbach's alpha (Taber 2018). This showed a satisfactory level of consistency, pre- and post-test. This modification has contributed to the literature and validated the theoretical

framework, in the relationship of PFCC and families assisting with passive exercises in ICU in relation to nursing stressors. This has not been previously noted.

The mNSS pre- and post-test results for both the active and the control units were compared. The results were analysed by: the means' of the individual items; the grouped items for the eight factors; the total mean score; years of nursing; and years nursing in ICU.
The purpose of the comparison was: to determine the highest and lowest workplace stressors for each cohort of nurses; and, also to see if the intervention of passive exercises had any impact on these stressors. The results were also compared to the results of other studies that had used the NSS in its original or modified form, as shown in Table 7.3 (French et al. 2000; Gray-Toft & Anderson 1981b; Healy & McKay 2000; McCarthy, Power & Greiner 2010; Rolf 1999).

Table 7. 3: Comparative NSS studies

Authors	Setting	Aim	Tool	Sample size	Findings
Gray-Toft (1981) USA	Private general hospital 5 units: medical surgical cardiovascular oncology hospice	Causes and effects of nursing stress in the hospital environment	34 item 7factors	122 RN	Three major sources of stress: Workload Feeling inadequately prepared to meet the emotional demands of patients and their families Death and dying Stress and staff turnover was greater for nurses with increased responsibility.
Rolf (1999) USA	300 bed tertiary referral hospital 2 critical care units 3 non-critical care	Acute care nursing: are perceived work stressors different for nurses working in critical care and non-critical care areas	34 item 7factors	131 RN and LPN	Workload and death dying factors scored higher in the critical care units. Inadequate preparation Lack of staff support and conflict with other nurses ranked lower
French et al. (2000) Canada	Multiple settings	Development of an expanded NSS Identify stressful situations not present in NSS Test reliability and validity of eNSS	57 item 9 factors	2280 RNs and LPN	They identified that the different nursing positions changed the stressors.

Authors	Setting	Aim	Tool	Sample size	Findings
Healy and McKay (2000) Australia	Metropolitan Melbourne and regional Victoria. Private and public hospitals	Nursing stress: the effects of coping strategies and job satisfaction in a sample of Australian nurses	34 item 7factors	129 RNs	Workload the highest stressor Conflict with other nurses and lack of support least stressful
McCarthy, Power & Greiner (2010) Ireland	Teaching hospital 10 different specialty units including wards, OPD, ICU and ED	To examine the levels of stress experienced by nurses working in an Irish teaching hospital and investigate differences in perceived stress by ward areas and associations with work characteristics	34 item 7 factors	117/186 (62%) 76% RNs 46% < 10 years	Perceived stress levels were higher in ICU workload
Dixon (2019) Sydney Australia	2 general medical and surgical ICUs public hospital Sydney Australia	To assess whether an intervention, in this case, family assisted passive exercising, would improve the stress levels and satisfaction of ICU nurses	Modified NSS 37 items 8 factors	Pre-study active unit 45/56 (80%) control unit 55/67 (82%) Post study active unit 40/58 (69%) control unit 40/47 (85%)	The complete results are in Chapter 5 and discussed below. In summary: Pre-test there was minimal differences between the active and control units with respect to the highest and lowest mean scores of individual stressors. Nurses found items in death and dying and workload factors the most stressful There was a correlation between years of nursing in ICU and years nursing. Years of experience changed the ranking of stressors

Pre-test there was minimal differences between the active and control units with respect to the highest and lowest mean scores of individual stressors. The top stressor pre-test for both units and comparable to other studies was from the death and dying factor, *watching a patient suffer* (Gray-Toft & Anderson 1981b; McCarthy, Power & Greiner 2010; Rolf 1999). Families ranked *to talk about the possibility of the patient's death* as one of the least met needs on the NMI. These two responses are aligned and as discussed in Section 7.3, this has been addressed within the ICU as an area for service improvement within the multi-disciplinary team and the introduction of the scenario based HELP training. It has previously

been noted that nurses experience stress when they have inadequate information or skills to answer the questions of families (Davidson 2009). This training would not only enable staff to have the difficult conversations with families but would help address families' needs as discussed above.

Four of the five top stressors pre-test were still ranked in the top five stressors post-test, although in a different order. The stressor *talking to family members,* which was one of the additional questions, went from the fourth most frequent stressor to the most frequent stressor. This was surprising given that the focus groups talked about the positive experiences in communicating with the families. This could be assumed to align with the discussions around end-of-life care that nurses found difficult to have. It is anticipated that this stressor, will be addressed with the HELP training course.

Nurses in both the active and control units also ranked *not enough staff to adequately cover the unit* and *unpredictable staffing and scheduling* from the workload factor as high stressors. These findings also supported previous research from both Australia and the USA, presented in Table 7.3 (Gray-Toft & Anderson 1981b; Healy & McKay 2000; McCarthy, Power & Greiner 2010; Rolf 1999)

The stressors were consistently scored across both the active and the control units. However, the years of experience in both units changed the ranking of the stressor. The more senior nurses, who were more likely to have managerial responsibilities, ranking questions in the workload factor, *not enough staff to adequately cover the unit* and *unpredictable staffing* as well as *talking to family members* from the study specific factor, higher than the more junior nurses (French et al. 2000; Kean & Mitchell 2014; McCarthy, Power & Greiner 2010; Rolf 1999). The more junior nurses ranked, *watching a patient suffer* from the death and dying factor and *floating to other units that are short staffed,* from the workload factor, higher than the more senior staff (McCarthy, Power & Greiner 2010). The explanation for this is the way that duties are allocated in an ICU. The more senior nurses are given the responsibility of coordinating the shift and managing resources, and the results demonstrated this with more senior nurses ranking the workload factors higher than their more junior colleagues. Whereas, the more junior nurses who are providing patient care, are impacted by the stressors associated with that, such as, talking to the families and patients dying (McCarthy, Power & Greiner 2010; Rolf 1999).

There was improvement in six of the eight factors pre-to post-test for the active unit including: death and dying; conflict with physicians; lack of support; conflict with other nurses; workload; and uncertainty concerning treatment. There was no change in the factor, inadequate preparation. This was not matched in the control unit where four factors were worse post-test including: lack of support; conflict with other nurses; workload; and the study specific factor.

The mNSS results from both the active and the control units were combined pre-test and analysed using non-parametric rank correlation to determine whether, the years of experience in nursing or in ICU nursing had any significance in relation to the stressors. The results presented in Chapter 5 demonstrated that: there was a correlation between years of nursing experience and years nursing in ICU. Importantly, the strongest item correlation was: *not knowing what a patient or a patient's family ought to be told about the patient's condition and its treatment*. The strongest factor correlation related to Factor 7, uncertainty concerning treatment. This was the same across both the active and control units and has added to the theoretical knowledge in how the stress scale functions and that experience, or lack thereof, drives stressors (McCarthy, Power & Greiner 2010).

These findings have given the impetus for tailored education and working groups in relation to these aspects of workplace stressors. It has also identified the issues around communication with families that can be addressed by the HELP course and the end-of-life working party. One of the aims of the end-of-life working party is to improve the nurses' communication skills so they are more comfortable talking to families.

A limitation of the original NSS, as recognised by the designers, is that the instrument measures the frequency with which certain situations are perceived as stressful by nurses, however it does not identify the intensity of the stressor (Gray-Toft & Anderson 1981b). It has been suggested that more focus should be diverted towards perceived intensity and frequency of stressful situations (Abbas, Farah & Apkinar-Sposito 2013). This was seen as a limitation of the research design and for future research it would be beneficial to use not only the NSS, but also an instrument that can measure the intensity and frequency of stress such as the Job Stress Survey (Nelson 2009; Rothmann, van der Colff & Rothmann 2006; Spielberger & Vagg 1999).

7.6 Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for patients and the healthcare system?

This question was tested by the gathering of: muscle measurements from the patient; the collation of ventilator hours; length of stay in ICU; length of stay in the hospital; and, mortality of the patient. This was achieved using the purpose designed FAPEI, which aligned to the outcome component of the SPO model that made up part of the theoretical framework for family assisted passive exercising in ICU (Donabedian 1988).

This section will discuss the clinical outcomes for the patient and the healthcare efficiencies in tandem as some of the measures cross over both elements. It will also discuss any limitations of the research, the contribution that the study has given to the literature, and finally, identify areas for future research.

7.6.1 Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for patients?

This question was tested measuring muscle mass with ultrasound technology and a tape measure during the patients' admission in ICU. When the patient was discharged from the ICU, the data of ventilator hours, length of stay in ICU, hospital length of stay and mortality were extracted from the EMR and entered into the FAPEI.

Research suggests that the impact of interventions of PFCC and family involvement in care improves patient outcomes (Johnson, Abraham & Shelton 2009). However, the research is still limited and inconclusive (Goldfarb et al. 2017; Mackie, Mithcell & Marshall 2016). This study aimed to evaluate an intervention, using the theoretical framework of family assisted passive exercising in ICU, to see whether it could improve patient outcomes (Donabedian 1988). It has already been observed that the patients in this study were extremely unwell. There were 808 patient admissions to the active and control units requiring mechanical ventilation in the 12-month period when the study took place. However, some patients got better more quickly than had been anticipated and some deteriorated or were palliated towards end-of-life care, excluding them from this study. Future research would require a

revision of the patient inclusion and exclusion criteria as arguably for this study they were too restrictive as there were limited patients that met the selection criteria. This was identified as a limitation of the study.

As already highlighted in Chapter 4, the mortality rate for all the enrolled patients was 37% and 26% for the patients whose families completed all parts of the study. This far exceeded the study site ICU average of 10%. Of the five patients lost to follow up who did not die: one was transferred to another facility for specialist treatment after losing all limbs to meningococcal disease; one patient was discharged home from the ICU on a weekend; and the other three families, despite follow up by the ICU CNC, failed to return the NMI post-test. The impact of the attrition was that the sample size was small.

As mentioned in Chapter 3, the APACHE II prognostic system (Knaus et al. 1985) was considered for the assessment of suitability of inclusion of the patients, but was not readily available at the time of the study. Eventually, the tool became available and the required data for the first 24 hours of admission, for all the study patients, was then entered retrospectively into the tool. The results were analysed to see if this would have been a better selection tool for the study given the large number of patients who died. However as can be seen in Table 7.4 neither the APACHE II Score, or risk of death were good indicators for these cohorts of patients as to who was likely to survive or die. In the active unit for example, the patients that survived had a higher score than the patients who died. Given the scores it was remarkable that more patients did not die, and this could be considered testament to the high quality care provided in the ICUs.

Table 7. 4: Retrospective APACHE II Score on all enrolled patients

	Active unit survived		**Control unit survived**		**Active unit died**		**Control unit died**	
	APACHE II Score	APACHE Risk of death %	APACHE II Score	APACHE Risk of death %	APACHE II Score	APACHE Risk of death %	APACHE II Score	APACHE Risk of death %
Mean	27.9	63.2	23.4	48.0	19.3	38.7	25.4	59.2
Range	19-33	18.2-84.5	13-37	24.6-86.8	14-27	18.6-60.5	14-30	18.6-77.2
SD	3.9	18.6	7.2	22.3	6.8	21.0	5.2	18.4

(The higher the score from 0-71 based is an indicator of more severe disease and higher risk of death)

Prior to the study commencing it was hoped that passive exercising may reduce muscle wasting and therefore improve the clinical outcome for the patient. To demonstrate this, as already mentioned, it was agreed that the muscle measurements would be taken using ultrasound technology and a tape measure. This was to be done at baseline once the patient was enrolled and then at a second and third point during their ICU stay. The coordination of the ultrasound measurement taking proved difficult. The study was deliberately designed in that one person was to take the measurements to attempt to eliminate bias. However, it was onerous for one individual to maintain momentum for a full year, with only 74% of the patients having any measurements taken. There was also, no consistency with when in their admission these measurements were done. This may be partially explained by the fact that the admissions were unplanned and occurred at all times of the day and days of the week.

The only conclusion to draw from the data of the patients whose muscles were measured was, that they all lost muscle mass. This confirmed previous research that prolonged episodes of bed rest caused muscle wasting (Jolley, Bunnell & Hough 2016; Schweickert & Hall 2007). Future research of this nature would require a different approach to muscle measuring, say, in that more people need to be able to take the measurements.

Analysing the data from the 19 patients that were included in the study showed that: ventilator hours were as short as 20 hours and as long as 1021 hours. The explanations of the shorter periods were either because the patient rapidly improved, or the decision was made to palliate them. The mean length of stay in the ICU for these patients was 22 days. This was higher than the median of 3.75 days, obtained from the EMR for all ICU patients for the same period. This was attributed to the seriousness of the patients' medical condition.

7.6.2 Can family assisted passive exercises on unconscious patients in an intensive care unit achieve better outcomes for the healthcare system?

This question was tested collecting the same patient data in the FAPEI, of ventilator hours, length of stay in ICU, hospital length of stay and mortality. The purpose of the FAPEI was: to determine if the family assisted passive exercising in ICU improved these outcomes. It was anticipated that the passive exercising of the patient may reduce muscle wasting. This in turn would lead to reducing the number of hours that the patient required mechanical ventilation and length of stay in the ICU and the hospital.

As discussed in Chapter 1, the first day in an ICU is approximately four times as expensive, and other ICU days are approximately three times as expensive, as non-ICU hospital days (Page, Barnett & Graves 2017; Pastores, Dakwar & Halpern 2012; Rapoport et al. 2003). The assumption was that, if the length of stay could be reduced by the intervention in this study, this would then translate into a financial saving for the hospital.

However, post-study, it is recognised that the true financial impact of a PFCC study is difficult to measure as most of the cost savings are indirect. For example, reducing the ventilator hours and length of stay for one patient does obviously improve efficiencies by reducing the variable costs such as intravenous fluids and dressings (Page, Barnett & Graves 2017). However, it does not negate the fixed costs required to use the same bed and nursing staff for another patient. Length of stay in the ICU is a common outcome measure (Cox et al. 2007; Stone et al. 2007; Wilcox et al. 2019) in randomised trials of ICU, but as many patients die in ICU, it is difficult to attribute an intervention on length of stay from the effects of mortality (Lin et al. 2017). In this study the high death rate impacted on any meaningful conclusions for the patient and the healthcare system. This is recognised as a focus for future research as despite the significant cost burden of ICUs there is limited research in this area (Wilcox et al. 2019).

As presented in Chapter 4, the mean measurements of ventilator hours, ICU and hospital length of stay for all of the patients in the study were worse than the means for the four ICUs combined for the same period. Plus the mortality rates as discussed were much higher for these patients. Length of stay in ICU was less in those lost to follow-up and there was a correlation between this and the increased rate of mortality in this cohort of patient. The results of the remaining patients showed the mean ventilator hours and length of stay in ICU were longer and mortality rates lower in the active unit, whereas the mean length of stay in the hospital was longer and the mortality rate was higher in the control unit. Due to these findings no further costing was attempted as it would have been futile.
The theoretical framework for this study in regards to PFCC was validated in regards to the family and nurses (McCormack & McCance 2006; Picker Institute 2008). However, the outcomes for the patient and the healthcare system remain inconclusive.

7.5.3 Focus groups

The focus groups as discussed in section 7.3.5, were a smaller part of the study that were held to triangulate the data from the quantitative instruments, and to obtain a greater understanding of the nurses' perspective on PFCC. In relation to the nurses, a particular focus was finding out from the groups, whether the study had been a positive or negative experience for them. Two of the nurses in the control unit stated that some nurses had questioned the beneficence of the exercises. However, on the whole, the nurses in all groups had felt comfortable in explaining the study. Overall, the view was that rather than the study and the intervention being burdensome, it assisted with the workload and increased staff satisfaction. This was in keeping with a previous Australian study that indicated that when nurses partner with families to deliver care, there was a minimal effect on their workload (Kean & Mitchell 2014). The study was also seen as an opportunity to focus back in on the patient rather than the technology of the machinery that ICUs are renowned for (Burr 1998; Hetland et al. 2018).

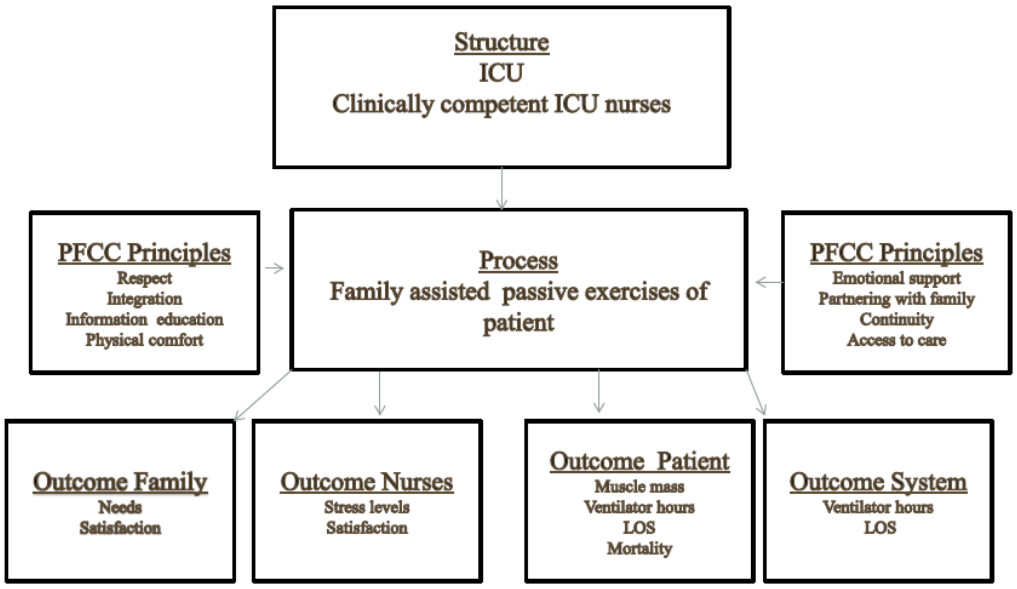
These findings validated the partnering with families component of the PFCC principles of the theoretical framework (ACSQHC 2017; McCormack & McCance 2006; Picker Institute 2008) and the outcomes component of the SPO model (Donabedian 1988). It also demonstrated that the theoretical framework for family assisted passive exercising in ICU, helped develop the attributes of the nurses with respect to PFCC (McCormack & McCance 2006).

7.7 Analysis considering the theoretical framework

As discussed in Chapter 2, PFCC is an established approach to the planning and delivery of care that encourages clinicians to partner with patients and their families. On examining the literature there were many definitions of PFCC, but no consistent theoretical framework used in PFFC studies to address research questions (Kitson et al. 2013). The research revealed a variety of theories, frameworks and instruments including: Bertalanffy's General System Theory (O'Neill-Norris & Grove 1986); family systems theory and crisis theory (Maxwell, Stuenkel & Saylor 2007) family-focused intensive care nursing (Coyer 2004), Kolcaba's comfort theory (Nolen & Warren 2014); person-centred nursing framework (McCormack & McCance 2006) the CCFNI (Molter 1979) and NMI (Warren 1994).

Even though these frameworks were examined and considered, as all studies have unique aspects, there was no research: that seemed to encompass all aspects of this study; or any that could be found with families assisting with passive exercises. The literature review also highlighted that, although the CCFNI has been widely used in PFCC studies, those that explored interventions assisting with meeting family needs were limited (Baning 2012; Kean & Mitchell 2014; Mitchell et al. 2009; Nolen & Warren 2014). Therefore, the theoretical framework for family assisted passive exercising in ICU (Figure 7.1) was developed to assess the impact of this intervention on PFCC outcomes. The framework has been a unique contribution of this research.

Figure 7. 1: Theoretical framework for family assisted passive exercising in ICU



This framework is purposed designed and, as discussed in Chapter 2, draws on a combination of frameworks and instruments to explore the issues for the, families, nurses, patients and healthcare system (Donabedian 1988; Gray-Toft & Anderson 1981b; McCormack & McCance 2006; Molter 1979; NHS 2012; Picker Institute 2008; Warren 1994). The objective of this section of the thesis is to: articulate the mapping of the thesis findings to this framework; and to demonstrate how this unique combination coalesced and was able to demonstrate its applicability to the elements under study. The findings support the benefits of this combined framework.

The overarching SPO framework (Donabedian 1988) was chosen as the foundation for the study's theoretical framework as it has been previously reported that improvements in the structure of care should lead to improvements in clinical processes and, that should, in turn, lead to improved patient outcomes (Donabedian 1988; Rathert, Wyrwich & Boren 2012). The SPO framework was also used to guide the person-centred nursing framework (McCormack & McCance 2006), which informed the clinically competent ICU nurses in this study. The third aspect of the study was the principles of PFCC (ACSQHC 2010; Picker Institute 2008). These combined frameworks in conjunction with the instruments of: CCFNI, NMI, FSS, mNSS, focus groups and FAPEI, aligned to the study objectives. That is: meeting families' needs and improving their satisfaction; reducing nurses' stress levels and improving their satisfaction; and, reducing patient muscle wasting and mortality, ventilator hours and length of stay in ICU and the hospital.

As shown in Figure 7.1, the *structure* (Donabedian 1988) was categorised as the active and control units and the ICU nurses where the study took place. This study has demonstrated that this framework, gives a *structure* (Donabedian 1988) that supports PFCC principles (ACSQHC 2010; Picker Institute 2008) and engagement of families and clinically competent ICU nurses (McCormack & McCance 2006) in the *process* (Donabedian 1988) of family assisted passive exercising. The following four sections will discuss the *outcomes* for all the elements of the study and how they were influenced by the *structure* and *process* (Donabedian 1988).

7.7.1 Outcome for families

As discussed above Donabedian's (1988) *structure, process, outcome* model was the foundation of the theoretical framework for family assisted passive exercising in ICU. The active and control units provided the venue for the study and the clinically competent direct care nurses (McCormack & McCance 2006) from both units provided either the exercises or the education and support for the families to do the exercises. The PFCC principles (ACSQHC 2010; Picker Institute 2008), built on the framework and the outcomes for the families were measured using the CCFNI (Molter 1979), NMI (Warren 1994), FFS (NHS 2012) and focus groups. The purpose of which was to determine whether the intervention of family assisted exercises *(process)* could address family needs and improve their satisfaction.

Table 7. 5 summarises how the principles of PFCC were met in this study.

Table 7. 5: The outcomes of PFCC principles

Principle	*Explanation	Outcomes
Respect for patient preference	Refers to involving and listening to patients and their families in decision-making. It is about recognising and honouring what may be unique perspectives and choices based on the diversity of cultural backgrounds.	The families, who were from many cultural backgrounds, were invited to participate in this study. The feedback received from the CCFNI and NMI has been acted on to improve systems issues. The study has given the nurses across both units a greater understanding of families' needs.
Coordination and integration of care	Patients expressed feeling vulnerable and powerless in the face of illness. Patients identified three areas in which care coordination can reduce feelings of vulnerability: • Coordination of clinical care • Coordination of ancillary and support services • Coordination of front-line patient care	Patients were not surveyed due to their medical condition. The approach of this study did foster coordination of front-line patient care with the nurses and families.
Information and education	Patients expressed their worries that they were not being completely informed about their condition or prognosis. To counter this fear, ICU's and hospitals can focus on three kinds of communication: • Information on clinical status, progress and prognosis • Information on processes of care Information to facilitate autonomy, self-care and health promotion	Information and education was provided to families in relation to the study and exercises. The domain of information in the CCFNI and NMI, measured this principle of PFCC. Families ranked the domain of information high pre-test on the CCFNI, post-test the NMI results did not score as high and has demonstrated that there are areas for service improvement. Particularly in notifying families of changes in the patient's condition.
Physical comfort	The level of physical comfort patients report has a significant impact on their experience. Three areas were reported as particularly important to patients: • Pain management • Assistance with activities and daily living needs • Hospital surroundings and environment	It was anticipated that the exercises would reduce muscle wasting and therefore enable patients to recover quicker post-ICU. This was not demonstrated. However, one patient when regaining consciousness requested the exercises as it gave him comfort.
Emotional support	Fear and anxiety associated with illness can be as debilitating as the physical effects. Caregivers should pay particular attention to: • Anxiety over physical status, treatment and prognosis • Anxiety over the impact of the illness on themselves and family • Anxiety over the financial impact of illness	The emotional support in this study related to the families and was measured using the CCFNI and NMI, in particular the assurance domain which the families ranked as one of the highest domains in both units. The study highlighted that nurses' perception of families' needs do not always correlate to what families perceive they need. However, a PFCC intervention can improve nurses' perception and improve families' needs and satisfaction.
Involvement of family and friends	This principle addresses the role of family and friends in the patient experience. Family dimensions of patient-centered care were identified as follows: • Providing accommodations for family and friends • Involving family and close friends in decision making • Supporting family members as caregivers • Recognizing the needs of family and friends	This was the foundation principle for the study. Partnering with families to assist with the passive exercises of their unconscious relative. The principle was measured using the CCFNI, NMI, FFS and focus groups.
Continuity and Transition	Patients expressed concern about their ability to care for themselves after discharge. Meeting patient needs in this area requires the following:	This was not fully explored in the study. However, the demographics of the patients meant that families were fully

Principle	*Explanation	Outcomes
	• Understandable, detailed discharge information i.e. in regards to medications, physical limitations, dietary needs • Coordinate and plan ongoing treatment and services after discharge • Provide information regarding access to clinical, social, physical and financial support on a continuing basis	supported by the multi-disciplinary team, that included not only the nursing and medical staff but social work, chaplaincy, physiotherapy and dietetic staff.
Access to care	Patients need to know they can access care when it is needed. Focusing mainly on ambulatory care, the following areas were of importance to the patient: • Access to the location of hospitals, clinics and physician offices • Availability of transportation • Ease of scheduling appointments • Availability of appointments when needed • Accessibility to specialists or specialty services when a referral is made • Clear instructions provided on when and how to get referrals	This was not fully explored in the study. However, families were given open access to their relatives so they could participate in care. This open access has been extended to all ICU visitors.

*(Picker Institute 2008)

Overall, using the theoretical framework, family assisted passive exercising in ICU has given a better understanding of family needs in the ICU. It has shown that: participating in care improves communication between families and nurses (Auerbach et al. 2005; Bishop, Walker & Spivak 2013; Molter 1979; Olding et al. 2016; Rukstele & Gagnon 2013); and family experience improves when they participate in care (Azoulay et al. 2003; Bishop, Walker & Spivak 2013; Olding et al. 2016) as it gives them proximity to their relative and assurance that families need (Jacob et al. 2016; Maxwell, Stuenkel & Saylor 2007; Picker Institute 2008). However, families may need to be invited (Kean & Mitchell 2014) as they may not be aware that this is an option in such a critical environment.

The study has also identified some areas for service improvement and future research to ensure that the needs of families are more fully met. The *structure* of the theoretical framework encouraged experienced nurses in the ICU. The review of the results of the CCFNI from the nurses showed that, more experienced nurses by years nursing, did not always translate into a better understanding of family needs. This was explained by these nurses often being the shift coordinators and consequently, unlikely to be as involved in the direct care of the patient. Therefore, the definition of *experience*, rather than being measured in years, may be better if expanded to include adequately trained.

The findings from the NMI showed that, families' needs were not met in relation to death and dying and as will be discussed in Section 7.8.2, a topic that nurses found stressful to deal with

and subsequently avoided. Also, there appeared to be a breakdown in communication with families, about being informed of changes to the patient's condition, when families were not at the hospital. This is being addressed by the development of an admission process that will determine when families want to be contacted.

Other service improvement includes expanding PFCC initiatives to all of the four units at the study site. This should be in collaboration with the families as due to their pre-existing relationship with the patient, they will be better informed as to what their relative would want (Burr 1998). It is recognised that change often comes from the nurses, who may be ill-informed as to what families want and need as demonstrated in this study.

All of these findings demonstrate how the ICUs have encouraged partnerships between the families and the healthcare professionals in accordance with The National Safety and Quality Health Service (NSQHS) Standards, Standard 2 *Partnering with Consumers* (ACSQHC 2017). This is a good foundation for future studies to enhance PFCC and patient safety.

This study has identified areas for future research. First, there would be benefits to further exploring the families perspective of their experience as this is still limited (Wong et al. 2015) and was not comprehensively explored in this study. This would include family interviews, which would have provided a greater understanding of their experience (Burr 1998; Kentish-Barnes et al. 2015) as well as exploring the impact on the family of bereavement.

Second, the social implications for the families of ICU patients do not seem to have been fully explored (Olding et al. 2016). In particular, the impact of a husband being hospitalised and the consequential impact for their wife; and why it is that women have been identified in this and many of the studies examined as the carer or requiring proximity to the patient (Auerbach et al. 2005; Bailey et al. 2009; Gentry et al. 2014; Kinrade, Jackson & Tomnay 2010; Leske 1991; Maxwell, Stuenkel & Saylor 2007; O'Neill-Norris & Grove 1986; Obringer, Hilgenberg & Booker 2012; Olding et al. 2016).

Third, the impact of a patient being hospitalised away from their social networks such as those from regional NSW would be an area for further research. Finally, examining the needs

of families from culturally and linguistically diverse backgrounds is a further avenue for consideration to help improve the family experience in the ICU.

7.7.2 Outcome for nurses

It was important that the nurses were clinically competent (Donabedian 1988; McCormack & McCance 2006) as they were integral in either, doing the passive exercises, or educating and assisting the families do the exercises. Prior to the study commencing, it was unclear what the *outcome* would be for the nurses in participating in this PFCC study. Whether , it would be perceived as an added challenge to their workload (Lee et al. 2007; Rippin et al. 2015) or decrease their satisfaction (Cappellini et al. 2014; Kean & Mitchell 2014; Lee et al. 2007). It was hoped rather, that as with previous research, that PFCC would increase family satisfaction and this in turn would increase the nurses' satisfaction (Charmel & Frampton 2008; Luxford & Newell 2015) which would ultimately improve the quality of patient care and family support (Flinkman, Leino-Kilpi & Salanterä 2010; Goldfarb et al. 2017).

To measure the impact of the study, nursing stress was measured using the mNSS (Gray-Toft & Anderson 1981b) and the focus groups. The findings from the mNSS pre- and post-test from the nurses of the active and control units has given a good understanding of nursing stressors at the study site and given baseline data for future research. This will enable the units to evaluate whether the changes made in this study in relation to PFCC are sustainable in reducing nursing stress.

The current findings showed that the nurses found: the items in the death and dying and workload factor the most stressful; and, that the intervention of family assisting with passive exercising partially relieved these stressors. This was demonstrated with a greater improvement in the mean score of the stressors for the nurses of the active unit not matched by the results from the nurses of the control unit. It was also identified that, years of experience as a nurse and as an ICU nurse, impacts on the way stressors are perceived. This has helped inform nursing training and education within the ICUs in regards to these stressors. These findings support the theoretical framework in relation to: family assisted passive exercises on unconscious patients in an ICU achieving better outcomes for nurses.

The modification to the NSS has contributed to the knowledge in elaborating the concept of PFCC and families assisting with passive exercises in ICU, in relation to nursing stressors. Additionally, the modification and implementation of the NSS has made a methodological contribution to the knowledge that has not been previously noted. An area for future research would be to not only identify workplace stressors for nurses, but to also explore the intensity of these stressors (Nelson 2009) , as this was not done in this study and had previously been identified as a limitation of the NSS (Gray-Toft & Anderson 1981a).

7.7.3 Outcomes for the patient

The *structure* of the ICU (Donabedian 1988) and the clinically competent nurses (Donabedian 1988; McCormack & McCance 2006) were integral in this PFCC study, to ensure that the *process* (Donabedian 1988) of passive exercises of the patient would occur. That is, either by the nurses or with the assistance of the family.

The benefits often associated with PFCC such as patient satisfaction could not be measured in this cohort of patients. The literature in relation to the outcomes for unconscious patients of PFCC informed approaches in the ICU setting was limited as the benefits tended to be more family focused (Bailey et al. 2009; Goldfarb et al. 2017; Maxwell, Stuenkel & Saylor 2007; Molter 1979) . This was an identified gap in the knowledge that this study sought to address. Previous research reported that a PFCC approach may improve clinical outcomes for the patient and enhance their recovery process (Azoulay et al. 2003; Damboise & Cardin 2003; Davidson 2009; Luxford & Newell 2015; McAdam, Arai & Puntillo 2008; Rukstele & Gagnon 2013). Potential benefits that were noted, included: reducing ventilator hours and length of stay with early mobilisation of patients (Damboise & Cardin 2003; Kress & Hall 2014; Morris et al. 2008; Rukstele & Gagnon 2013) as well as reducing mortality (Meterko et al. 2010). Therefore, it was decided to use these measures of clinical outcomes in this study. The outcomes for the patient were measured using: ultrasound technology and a tape measure to assess their muscles; and the FAPEI, recorded mortality, ventilator hours and length of stay in the ICU and the hospital.

As discussed previously, the predicted improvements for the patient with the *process* of the passive exercises did not eventuate. It could be argued that this study was too ambitious with

this cohort of patients. In future studies, researchers need to carefully consider the inclusion and exclusion criteria for the patients. More recent review of the literature, still demonstrates that there is no well-defined solution for stopping muscle wasting and weakness (Hodgson & Tipping 2017) or mortality (Goldfarb et al. 2017). These would be suggested areas for further research. Since the conclusion of this study two multi-centre studies are being conducted in the ICUs, looking into ICUAW and mobilisation of ICU patients and include: Treatment of invasively ventilated adults with early activity and mobilisation (TEAM) trial and a randomised controlled trial in extracorporeal membrane oxygenation physical training (ECMO-PT).

Although these findings did not clearly support that family assisted passive exercises on unconscious patients in an ICU can achieve better outcomes for the patient, it can be argued that PFCC due to its very nature, has benefits that metrics do not always capture. This study using PFCC principles (ACSQHC 2010, 2017; Picker Institute 2008) involved family members and friends in the care of their relative, who were then able to provide emotional support to the unconscious patient and help provide physical comfort. Hence, having your family member alongside you when you are so unwell can be considered beneficial (Bishop, Walker & Spivak 2013; Goldfarb et al. 2017; McAdam, Arai & Puntillo 2008; McCormack & McCance 2006; Molter 1979; Nelson et al. 2010; Picker Institute 2008; Wyskiel et al. 2015) as they can be your advocate, protector and provide reassurance (Hardin 2012; Mackie, Mitchell & Marshall 2018). The patient vignettes presented in the statement of the problem in Chapter 1 helps illustrate these points.

7.7.4 Outcomes for the healthcare system

It was established in the introduction to the thesis that, the cost of keeping a patient in the ICU is more expensive than care that is provided in a ward (Berney, Haines & Denehy 2012; Page, Barnett & Graves 2017; Pastores, Dakwar & Halpern 2012) . Previously, research in relation to early physical therapy in ICU patients has demonstrated a possible reduction in resource utilisation (Charmel & Frampton 2008; Green et al. 2016; O'Connor & Walsham 2009; Vasilevskis et al. 2010). This was achieved by reducing: mortality; duration of mechanical ventilation by improving muscle strength; and hospital and ICU length of stay (Morris et al. 2008; O'Connor & Walsham 2009; Winkelman et al. 2012). However none of

this research was with family-assisted therapy. This study sought to see if a PFCC intervention, namely, family assisted therapy, could have a positive outcome for the healthcare system. This was to be achieved by, reducing the time that the patients required mechanical ventilation and subsequently the length of stay in the ICU and the hospital. This was measured by extracting the same data that were extracted for the patient from the patients' EMR and entering it into the FAPEI.

As with the patient *outcomes* these findings did not support that family assisted passive exercises on unconscious patients in an ICU achieved the expected *outcomes* for the healthcare system. However, the fact that the ICUs have implemented PFCC and are expanding this across all of the units is a testament to the success of the study. PFCC and supporting families to assist with care in this study benefitted the healthcare system short term, by enhancing the reputation of the ICUs and the hospital. Long term with further research it is anticipated that it can be demonstrated that PFCC in the ICU does contribute to better outcomes and experiences for patients and their families (ACSQHC 2018) (The Health Foundation 2014a).

7.8 Conclusion

In this chapter the outcomes of the study for the families, nurses, patient and healthcare system have been examined. This showed that the intervention of family assisted passive exercising did not prevent muscle wasting in ICU patients. However, the findings support the proposition, that family assisted passive exercise, designed and implemented with the principles of PFCC, can enhance family and nurses satisfaction in the ICU.

The study confirmed that family experience and satisfaction improved when they participated in care (Goldfarb et al. 2017; Mitchell & Chaboyer 2010). This can be attributed to the fact: their needs were met, as family assisting with care gives proximity to their relative and assurance that families' need, as identified in this and previous research (Bailey et al. 2009; Burr 1998; Kinrade, Jackson & Tomnay 2010; Maxwell, Stuenkel & Saylor 2007; Molter 1979; O'Neill-Norris & Grove 1986). It is still unclear if families would ask to provide care to their relative (Agard & Harder 2007; Kean & Mitchell 2014), rather, that they need to be invited. This can be attributed to how overwhelming the ICU environment is for most

relatives and also to the fact that ICU nurses may want to keep control over their environment (Kean & Mitchell 2014). This study demonstrated that when families feel welcomed by the nurses that they will ask to participate in care.

This study also confirmed improvements: in nurses' perception of families' needs; as well as communication between the family and nurses (Burr 1998; Kinrade, Jackson & Tomnay 2010; Mitchell & Chaboyer 2010). Additionally, it showed nurses' stress levels improved, that is decreased, with the group that partnered in care with the families.

Overall, this research has added to the body of knowledge: in that there has been limited research in relation to interventional PFCC improving outcomes (Goldfarb et al. 2017). The findings of this research concur with previous research in relation to the three individual frameworks (ACSQHC 2010; Donabedian 1988; McCormack & McCance 2006; Picker Institute 2008). It extends the knowledge base by showing that the combination of the three frameworks gives a broader, holistic integrated model for PFCC in the ICU.

The following chapter concludes this thesis by outlining the: unique contributions of the thesis; summary of the study findings; research limitations; directions for future research; and, application to clinical practice.

Chapter 8 Conclusion

This chapter brings the thesis to a close. It will present the: unique contributions of this thesis (section 8.1); summary of the study findings (section 8.2); research limitations (section 8.3); and, directions for future research and applications to clinical practice (section 8.4).

8.1 Unique contributions of this thesis

This thesis has contributed uniquely to the knowledge in four significant ways.

First, the development and testing of a purpose designed theoretical framework for family assisted passive exercising of unconscious patients. After a review of the literature identified a gap in a suitable framework, this unique blended framework was developed to focus on the specific variables of this study: the families, nurses, patients and healthcare system. The new framework used the foundation of the SPO quality model (Donabedian 1988) and integrated elements of the PFCC principles (ACSQHC 2010; Picker Institute 2008) and the person-centred nursing framework (McCormack & McCance 2006). The use of the CCFNI to measure the outcomes of an intervention and the FAPEI also added to the uniqueness of this framework. This study with its purpose designed theoretical framework for family assisted passive exercising in ICU has developed a new approach for research.

Second, the findings from the study demonstrated that when families and nurses interact in relation to a PFCC intervention such as, family assisted passive exercises; it helps to builds relationships and improves communication between the families and the direct care nurses. This helps to not only improve ICU families' satisfaction by meeting their needs, but helps reduce nursing stress levels of the direct care nurses who provide the support to ICU families. This insight in relation to a PFCC intervention improving nursing stress has not been previously noted in the literature. This is a unique contribution of this research. These findings endorse that family assisted passive exercise, designed and implemented with the principles of PFCC can enhance family and nurses satisfaction in the ICU.

There has been previous PFCC research, where families have assisted with care, however at the time this study commenced it was the first of its kind at the study site. This research has been unique in that, it is believed to be the only study in relation to families assisting with

passive exercises of their family member in an ICU. This supports the PCC principles of the theoretical framework and has, therefore, contributed significantly to the knowledge base, in particular for the Australian setting, but also its applicability to other contexts. There has been limited research in relation to interventional PFCC improving outcomes (Goldfarb et al. 2017). The intervention of family assisted passive exercising of unconscious patients in the ICU examined whether there were improvements for the families, nurses, patients and healthcare system. The findings support previous research in this regard (Goldfarb et al. 2017; Hardin 2012; Mitchell & Chaboyer 2010; Obringer, Hilgenberg & Booker 2012).

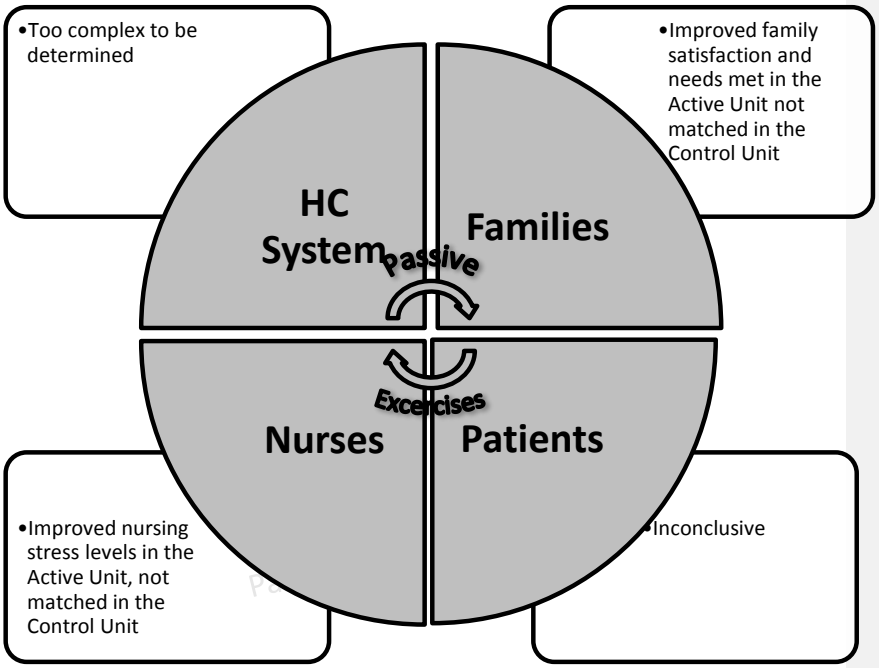
Third, this thesis has made a methodological contribution to the literature in elaborating the concept of PFCC and its impact on nurses' stress with the use of the mNSS. The modifications to the NSS (Gray-Toft & Anderson 1981b) were in recognition that the different clinical settings may have different stressors. In this study the aim was to have targeted questions that were specific to the intervention of family assisted passive exercises, to investigate how the intervention impacted on the direct care nurses. Therefore, this study has contributed to understanding the stressors experienced by Australian ICU nurses and how PFCC, in particular the intervention of family assisted passive exercises, can mitigate some of the stressors thereby, improving nurses' satisfaction. The modification has contributed to the literature and validated the theoretical framework, in the relationship of PFCC and families assisting with passive exercises in ICU in relation to nursing stressors. This has not been previously noted in the literature. This is a unique contribution of this research.

Fourth, the FAPEI was developed to collate the patient and family demographics and the study specific data for the patient and healthcare system in a rigorous, structured and systematic way. This instrument, although study specific can be easily replicated, and has given good baseline data for future research at the study site. This unique purpose designed tool is a further contribution of this research to the field. The tool can be used in other ICU settings to compliment other data collection strategies and provide a holistic investigation of the impact of significant immobility on patients.

8.2 Summary of the study findings

The outcomes of the research for: the families, patients, nurses and healthcare system are presented in Figure 8.1, followed by the concise answers to the research questions.

Figure 8. 1: Outcomes of research



8.2.1 Concise answers to the research questions

Can family assisted passive exercising of unconscious patients in an Intensive Care Unit achieve better outcomes for families?

This question was tested using the CCFNI, NMI and FSS instruments and the focus groups to determine if the intervention could assist with meeting the needs of families and improve their satisfaction. The results from each of these instruments have been presented in Chapter 4 and the focus group findings in Chapter 6. To summarise, the results of the CCFNI pre-test showed there was a difference of perception of family needs, between the families and nurses in both the active and control units. Post-test the nurses from the active unit showed greater improvement in perception of families' needs than their colleagues in the control unit. The results of the CCFNI completed by the families pre-test compared to the NMI completed by the families post-test showed that the support and comfort domain improved for the families of the active unit. There was only marginal improvement in the comfort domain for the families of the control unit.

The results of the FSS showed that all the participating families indicated they would highly recommend the service to friends and family if they needed similar care or treatment. The focus groups held with the nurses reported that families were reassured when they assisted with care and that they appeared more satisfied. This was attributed to the improvement in communication between the families and nurses, as a result of the nurses having to educate the families in relation to the passive exercises. The findings support that there were better outcomes for the families, in that there was greater improvement in the results for the families in the active unit where most of their needs were met.

Can family assisted passive exercising of unconscious patients in an intensive care unit achieve better outcomes for nurses?

This question was tested using the mNSS and the focus groups to determine if the intervention of could improve nurses' stress levels. The results of the mNSS were presented in Chapter 5 and the focus group findings in Chapter 6. To summarise, the results of the mNSS showed pre-test there was little difference between the active and control units with respect to the highest and lowest scoring stressors and factors.

Post-test there was greater improvement in the nurses of the active unit, not matched by the nurses of the control unit. The findings support that there were better outcomes for the nurses, in relation to reduced nursing stress levels.

Can family assisted passive exercising of unconscious patients in an intensive care unit achieve better outcomes for patients?

This question was tested using ultrasound and a tape measure to measure the patients' muscles to see if the exercises prevented muscle wasting, and the FAPEI which collected all the patient data. The patient data included in the FAPEI were: the muscle measurements; ventilator hours; length of stay in ICU and the hospital; and, health outcome. The results from this data were presented in Chapter 5 and the discussions in the focus groups in Chapter 6. The results showed that muscle wasting occurred across both cohorts of patients and the other measures were too disparate to draw a clear conclusion.

Nevertheless, as highlighted in Chapter 1, the family can be: an active presence watching over the patient; a surrogate decision maker and an advocate for the patient when they cannot advocate for themselves (Hardin 2012; Mackie, Mitchell & Marshall 2018); the historian providing the medical history, which will assist the medical and nursing staff provide optimal

and safe care (Hardin 2012); and, a voluntary caregiver and assist with treatments that are beneficial to the patient and provide physical comfort (Hardin 2012; Picker Institute 2008; Wyskiel et al. 2015). These benefits were observed in this study.

Can family assisted passive exercising of unconscious patients in an intensive care unit achieve better outcomes for the healthcare system?

This question was tested using the patient data included in the FAPEI of: ventilator hours; and, length of stay in ICU and hospital. It was anticipated, as with previous research, there may be a possible reduction in resource utilisation translating into financial savings (Charmel & Frampton 2008; Goldfarb et al. 2017; O'Connor & Walsham 2009; Vasilevskis et al. 2010). The anticipated reduction in mortality, duration of mechanical ventilation and hospital and ICU length of stay (Morris et al. 2008; O'Connor & Walsham 2009; Winkelman et al. 2012) did not eventuate. However, as discussed in Chapter 7, PFCC and supporting families to assist with care in this study benefitted the healthcare system short term by enhancing the reputation of the ICUs and the hospital.

8.3 Research limitations

This was a single site study. The service has multiple units with a mix of medical and surgical patients, and is comparable to other units across Australia and internationally. The approach and findings are transferable to other ICUs and hospital settings.

The thesis was limited by the cohort of patients and the inclusion and exclusion criteria which selected them. Although the study was to look at the impact that the intervention would have on unconscious patients it was unclear at the commencement of the study, actually how sick this cohort of patients would be. The attrition of families although not fully understood was partially explained by the fact that a higher proportion of patients in the study, than was usual for the study site, died. The attrition of families and the resulting sample size was a limitation and future research would benefit from a larger cohort of less critically ill patients and their families.

The family members were surveyed during the patient's admission. There is some suggestion that surveys given to families, during a patient's hospitalisation may influence how family members' respond (Gentry et al. 2014). There may be a reluctance to give negative feedback whilst a family member is in hospital for fear of retribution and that confidentiality assurance

is not always perceived as reassuring (Ermakova, Fabian & Zarnekow 2016; Singer, Hippler & Schwarz 1992). The lack of interviews with families, in either the form of group or individual interviews meant that the information from the families was not as comprehensive as that from the nurses.

A limitation of the NSS, as recognised by the designers, is that the instrument measures the frequency with which certain situations are perceived as stressful by nurses, it does not identify the intensity of the stressor (Gray-Toft & Anderson 1981b). It has been suggested that an improved focus would be to direct attention towards perceived intensity and frequency of stressful situations (Abbas, Farah & Apkinar-Sposito 2013; Leiter & Maslach 2016; Spielberger & Vagg 1999).

8.4 Directions for future research and application to clinical practice

The study was inconclusive with respect to improving patient and healthcare outcomes. It did, however, demonstrate that muscle wasting occurs in patients with prolonged stays in ICU. The research did not address how to prevent it happening and highlighted that there is still more research required in regards to ICUAW and its prevention and cure.

8.4.1 Research

Since starting this study, guidelines have been developed in NSW by the ACI, to assist ICU clinicians develop programs for critically ill patients from admission to discharge in relation to physical activity and movement (ACI 2014). Further studies have commenced at the study site in regards to ICUAW that include; Treatment of invasively ventilated adults with Early Activity and Mobilisation (TEAM) trial; and, a randomised controlled trial in extracorporeal membrane oxygenation physical training (ECMO-PT). These are multi-centre studies and this will hopefully provide further significant findings to improve care processes and outcomes.

Even though PFCC studies have been conducted in other ICUs, the imperative is to encourage all facilities and ICUs to conduct this type of research. This would continually improve the services they provide to their patients and families and develop the evidence base regarding PFCC outcomes (Baning 2012; Goldfarb et al. 2017). This study has generated

further interest regarding PFCC at the study site and consequently there are now other PFCC projects occurring in the other units.

For future research, there are benefits to further exploring the families perspective of their experience as this is still limited (Wong et al. 2015). This would include family interviews, which would provide a greater understanding of the whole construct in this study (Burr 1998) as well as exploring the impact on the family of bereavement. Second, the social implications for the families of ICU patients do not seem to have been explored. In particular, the impact of a husband being hospitalised and the consequential impact for their wife; and why it is that women have been identified in this and many of the studies examined as the carer. Third, the impact of a patient being hospitalised away from social networks such as those from regional NSW, and what PFCC means for them should be considered. Examining the PFCC needs of families from culturally and linguistically diverse backgrounds is also an important issue to focus upon. As PFCC is often based on staff perceptions it is vital that the families and patients are part of the solution, hence additional research with them is critical.

8.4.2 Application to clinical practice

A significant insight from the study is that discussions about death and dying remains an on-going challenge in the ICU for both the families and the nurses (Kentish-Barnes et al. 2015; Trankle 2014). This has been identified as an area for service improvement and has led to enhanced communication training for the nurses as well as the multi-disciplinary team with the scenario based HELP training course. This will assist the multi-disciplinary team with communication skills around talking to the families about end-of-life care and death and dying.

Another area for service improvement that was identified through the study was the need for families to be informed of changes in the patients' condition. This is currently being addressed through the nursing admission process.

This PFCC ICU study has highlighted the importance of nurses' partnering with families. It has shown that when these partnerships occur that communication is improved between the two groups. This is in contrast to previous work where family members declined to participate in care (Azoulay et al. 2003), but supports other research which showed that

families and ICU staff are very supportive of family participation in care (Garrouste-Orgeas et al. 2010). However, it can be argued that the care activities that families participate in should not be too clinical. At the study site, as well as passive exercises, information cards have been developed to assist families in all of the units, partner with nurses to provide care such as: hair brushing, hand massage, and eye and mouth care.

8.5 Conclusion

This thesis examined the impact of a PFCC on family assisted passive exercising of unconscious patients in the ICU, on the family, nurses, patients and healthcare system. This PFCC study had positive impacts in the ICUs, as relationships developed between the direct care nurses and the families, enhancing communication between them. Family assisted passive exercises helped to meet the needs of families and reduce nurses' stress. Even for the patients that did not survive their episode of illness, that having family members that were involved with their end-of-life care gave them some reassurance. For the healthcare system, although there were no discernible financial benefits or efficiencies associated with the study; PFCC supports a positive reputation of the organisation. This is summarised by the words of one of the family members who left a thank you card:

> *'I just wanted to pass on my heartfelt thanks and appreciation to everyone in the ICU for not only assisting my father with his stroke but also the amazing service, support and care that you gave to me and my family. I am so appreciative and thankful for you amazing ability to make us feel like we were welcome, you were so attentive not only to Dad but also to us making us feel so safe, supported and every single staff member we met went out of their way to show the same high level of care you gave Dad. I was so impressed with the outstanding care you provided not only to Dad but to all of our family. I can't thank you enough for the care and medical assistance. Without you, I'm sure Dad would not be here but also you made sure that the whole family were fully supported and welcome. Thank you'.*

References

Abbas, S, Farah, A & Apkinar-Sposito, C 2013, 'Measuring the immeasurable! An overview of stress & strain measuring instruments ', *Mediterranean Journal of Social Sciences,* vol. 4, no. 10, pp. 480-489.

Adams, J, Anderson, R, Docherty, S, Tulsky, J, Steinhauser, K & Bailey, D 2014, 'Nursing strategies to support family members of ICU patients at high risk of dying', *Heart & Lung: The Journal of Acute and Critical Care,* vol. 43, no. 5, pp. 406-415.

Agency for Clinical Innovation (ACI) 2014, *Physical activity and movement: A guideline for critically ill adults',* viewed 26 May 2015, http://www.aci.health.nsw.gov.au

Agency for Clinical Innovation (ACI) 2015, *Patient experience and consumer engagement. A framework for action,*viewed 26 May 2015, http://www.aci.health.nsw.gov.au

Al-Mutair, A, Plummer, V, O'Brien, A & Clerehan, R 2013, 'Family needs and involvement in the intensive care unit: a literature review', *Journal of Clinical Nursing,* vol. 22, no. 13-14, pp. 1805-1817.

Amidei, C & Sole, M 2013, 'Physiological responses to passive exercise in adults receiving mechanical ventilation', *American Journal of Critical Care, ,* vol. 22, no. 4, pp. 337-349.

Appelbaum, S, Habashy, S, Malo, J.-L & Shafiq, H 2012, 'Back to the future: revisiting Kotter's 1996 change model ', *Journal of Management Development,,* vol. 31, no. 8, pp. 764-782.

Atif, A., Richards, D & Bilgin, A 2013, 'A student retention model: empirical, theoretical and pragmatic considerations', *Proceedings of the Australasian Conference on Information Systems*. Melbourne, Australia. viewed 12 December 2018, https://researchers.mq.edu.au/en/publications/a-student-retention-model-empirical-theoretical-and-pragmatic-con

Auerbach, S, Kiesler, D, Wartella, J, Rausch, S, Ward, K & Ivatury, R 2005, 'Optimism, satisfaction with needs met, interpersonal perceptions of the healthcare team, and emotional distress in patients' family members during critical care hospitalization', *American Journal of Critical Care,* vol. 14, no. 3, pp. 202-10.

Australian Bureau of Statistics (ABS) 2015, *Sample size calculator,*viewed 14 March 2015, https://www.abs.gov.au/websitedbs/D3310114.nsf/home/Sample+Size+Calculator

Austrlian Bureau of Statistics (ABS) 2016, *Census QuickStats*, viewed 1 January 2020 https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/1,

Australian College of Critical Care Nurses, 2015, *Partnering with families in critical care-position statement,*viewed December 2018, https://www.acccn.com.au/documents/item/289

Australian Commission on Safety and Quality in Health Care (ACSQHC) 2010, *Patient centred care: Improving quality and safety by focusing care on patients and consumers,*viewed 6 May 2014, https://www.safetyandquality.gov.au/wp-content/uploads/2012/01/PCCC-Discussion Paper

Australian Commission on Safety and Quality in Health Care (ACSQHC) 2012, *National Safety and Quality Health Service Standards,*viewed 14 March 2015, https://www.safetyandquality.gov.au/wp-content/uploads/2011/09/NSQHS-Standards-Sept-2012.pdf

Australian Commission on Safety and Quality in Health Care (ACSQHC) 2017, *National Safety and Quality Health Service Standards. 2nd ed*. viewed 14 February 2019, https://www.safetyandquality.gov.au/our-work/assessment-to-the-nsqhs-standards/nsqhs-standards-second-edition/

Australian Institute of Health and Welfare (AIHW) 2012, *Australia's Health 2012: In Brief*, viewed 14 March 2015, https://www.aihw.gov.au/reports/australias-health/australias-health-2012/

Australian Institute of Health and Welfare (AIHW) 2017, 'Admitted patient care 2015–16. Australian hospital statistics', viewed 10 June 2019, https://www.aihw.gov.au/reports/hospitals/ahs-2016-17-admitted-patient-care/contents/table-of-contents

Azoulay, É, Pochard, F, Chevret, S, Arich, C, Brivet, F, Brun, F, Charles, P.-E, Desmettre, T, Dubois, D, Galliot, R, Garrouste-Orgeas, M, Goldgran-Toledano D., Herbecq, P, Joly, L.-M, Jourdain, M, Kaidomar, M, Lepape, A, Letellier, N, Marie, O, Page, B, Parrot, A, Rodie-Talbere, P.-A, Sermet, A, Tenaillon, A, Thuong, M, Tulasne, P, Le Gall, J.-R & Schlemmer, B 2003, 'Family participation in care to the critically ill: opinions of families and staff', *Intensive Care Medicine*, vol. 29, no. 9, pp. 1498-1504.

Azoulay, E, Timsit, J, Sprung, C, Soares, M, Rusinová, K, Lafabrie, A, Abizanda, R, Svantesson, M, Rubulotta, F, Ricou, B, Benoit, D, Heyland, D, Joynt, G, Français, A, Azeivedo-Maia, P, Owczuk, R, Benbenishty, J, de Vita, M, Valentin, A, Ksomos, A, Cohen, S, Kompan, L, Ho, K, Abroug, F, Kaarlola, A, Gerlach, H, Kyprianou, T, Michalsen, A, Chevret, S & Schlemmer, B 2009, 'Prevalence and factors of intensive care unit conflicts: the conflicus study', *American Journal Respiratory Critical Care Medicine*, vol. 180, no. 9, pp. 853-860.

Bailey, J, Sabbagh, M, Loiselle, C, Boileau, J & McVey, L 2009, 'Supporting families in the ICU: A descriptive correlational study of informational support, anxiety, and satisfaction with care', *Intensive and Critical Care Nursing*, vol. 26, no. 2, pp. 114-122.

Baning, K 2012, Outcomes of a comprehensive patient and family-centred care program in an adult intensive care unit, doctoral thesis, University of Arizona.

Barlow, P 2012, 'A practical review of the Glasgow Coma Scale and Score', *The Surgeon, Journal of the Royal Colleges of Surgeons of Edinburgh and Ireland*, vol. 10, no. 2, pp. 114-119.

Berney, S, Haines, K & Denehy, L 2012, 'Physiotherapy in critical care in Australia', *Cardiopulmonary Physical Therapy Journal*, vol. 23, no. 1, pp. 19-25.

Berry, M & Morris, P 2013, 'Early exercise rehabilitation of muscle weakness in acute respiratory failure patients', *Exercise and Sports Science Reviews*, vol. 41, no. 4, pp. 208-215.

Bijttebier, P, Delva, D, Vanoost, S, Bobbaers, H, Lauwers, P & Vertommen, H 2000, 'Reliability and validity of the Critical Care Family Needs Inventory in a Dutch-speaking Belgian sample', *Heart Lung*, vol. 29, no. 4, pp. 278-86.

Bishop, S, Walker, M & Spivak, I 2013, 'Family presence in the adult burn Intensive Care Unit during dressing changes', *Critical Care Nurse*, vol. 33, no. 1, pp. 14-24.

Black, P, Boore, JR & Parahoo, K 2011, 'The effect of nurse-facilitated family participation in the psychological care of the critically ill patient', *Journal of Advanced Nursing*, vol. 67, no. 5, pp. 1091-101.

Blanchard, D & Alavi, C 2008, 'Asymmetry in the intensive care unit: redressing imbalance and meeting the needs of family', *Nursing Critical Care*, vol. 13, no. 5, pp. 225-231.

Bloomer, M, Morphet, J, O'Connor, M, Lee, S & Griffiths, D 2013, 'Nursing care of the family before and after a death in the ICU. An exploratory pilot study', *Australian Critical Care*, vol. 26, pp. 23-28.

Braun, V & Clarke, V 2006, 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, vol. 3, pp. 77-101.

Brooks, L, Manias, E & Nicholson, P 2017, 'Communication and decision-making about end-of-life care in the intensive care unit', *American Journal of Critical Care*, vol. 26, no. 4, pp. 336-341.
Buckley, P & Andrews, T 2011, 'Intensive care nurses' knowledge of critical care family needs', *Intensive Critical Care Nursing*, vol. 5, pp. 263-272.
Buckley, T, Spinaze, M, Bartrop, R, McKinley, S, Whitfield, V, Havyatt, J, Roche, D, Fethney, J & Tofler, G 2015, 'The complex nature of practice and research in end of life and bereavement care in the critical care environment', *Australian Critical Care*, vol. 28, no. 2, pp. 64-70.
Burr, G 1998, 'Contextualizing critical care family needs through triangulation: an Australian study', *Intensive Critical Care Nursing*, vol. 14, no. 4, pp. 161-169.
Burtin, C, Clerckx, B, Robbeets, C, Ferdinande, P, Langer, D, Troosters, T, Hermans, G, Decramer, M & Gosselink, R 2009, 'Early exercise in critically ill patients enhances short-term functional recovery', *Critical Care Medicine*, vol. 37, no. 9, pp. 2499-2505.
Byrne, B 2016 Structural equation modeling with AMOS: Basic concepts, applications, and programming. Oxford: Routledge.
Callahan, L & Supinski, G 2013, 'Prevention and treatment of ICU-acquired weakness: is there a stimulating answer?', *Critical Care Medicine*, vol. 41, no. 10, pp. 2457-2458.
Camargo Pires-Neto, R, Fogaça Kawaguchi, Y, Sayuri Hirota, A, Fu, C, Tanaka, C, Caruso, P, Park, M & Ribeiro Carvalho, C 2013, 'Very early passive cycling exercise in mechanically ventilated critically ill patients: physiological and safety aspects, a case series.', *PLoS One*, vol. 8, no. 9, p. e74182, viewed 11 September 2014, doi: 10.1371/journal.pone.0074182
Campbell, I, Watt, T, Withers, D, England, R, Sukumar, S, Keegan, M, Faragher, B & Martin, D 1995, 'Muscle thickness, measured with ultrasound, may be an indicator of lean tissue wasting in multiple organ failure in the presence of edema', *American Journal Clinical Nutrition*, vol. 62, no. 3, pp. 533-9.
Cannon, S 2011, 'Family-centered care in the critical care setting: is it best practice?', *Dimensions of Critical Care Nursing*, vol. 30, no. 5, pp. 241-245.
Cappellini, E, Bambi, S, Lucchini, A & Milanesio, E 2014, 'Open intensive care units: a global challenge for patients, relatives, and critical care teams', *Dimensions of Critical Care Nursing*, vol. 33, no. 4, pp. 181-193.
Casarini, K, Gorayeb, R & Filho, A 2009, 'Coping by relatives of critical care patients', *Heart Lung*, vol. 38, no. 3, pp. 217-227.
Clinical Excellence Commission (CEC) 2015, *'Patient based care challenge'*, viewed 7 October 2016http://www.cec.health.nsw.gov.au/echartbook/cec-indicators-intro-echartbook/patient-based-care
Chaboyer, W, McMurray, A & Wallis, M 2010, 'Bedside nursing handover: a case study', *International Journal of Nursing Practice*, vol. 16, no. 1, pp. 27-34.
Chambers, M, Moylan, J & Reid, M 2009, 'Physical inactivity and muscle weakness in the critically ill', *Critical Care Medicine*, vol. 37, no. 10, pp. S337-S346.
Charmel, P, & Frampton, S 2008, 'Building the business case for patient centred care ', *Healthcare Financial Management*, vol. 62, no. 3, pp. 80-85.
Chen, X, Wang, Y, Wang, F & Agichtein, E 2015, *'A Comparative Study of Demographic Attribute Inference in Twitter'*,viewed 5 January 2019, https://pdfs.semanticscholar.org/0fe3/5d406842f054ce306ef67b20dc51a5a59dfd.pdf.
Cimiotti, J, Aiken, L, Sloane, D & Wu, E 2012, 'Nurse staffing, burnout, and health care–associated infection*' American Journal of Infection Control*, vol. 40, no. 6, pp. 486-490.

Ciufo, D, Hader, R & Holly, C 2011, 'A comprehensive systematic review of visitation models in adult critical care units within the context of patient- and family-centred care', *International Journal Evidence Based Healthcare*, vol. 9, no. 4, pp. 362-87.
Constand, M, MacDermid, J, Vanina Dal Bello-Haas, V & Law, M 2014, 'Scoping review of patient-centered care approaches in healthcare', *BMC Health Services Research*, vol. 14, no. 271, pp. 1-9.
Cook, D & Rocker, G 2014, 'Dying with dignity in the intensive care unit', *New England Journal of Medicine*, vol. 370, pp. 2506-2514.
Cornish, F. & Gillespie, A. 2009, 'A Pragmatist Approach to the Problem of Knowledge in Health Psychology', *Journal of Health Psychology*, vol. 14, no. 6, pp. 800-809.
Cox, C, Carson, S, Govert, J, Chelluri, L & Sanders, D 2007, 'An economic evaluation of prolonged mechanical ventilation', *Critical Care Medicine*, vol. 35, no. 8, pp. 1918-1927.
Coyer, F 2004, *The development of family-focused intensive care nursing through action research*, doctoral thesis, Queensland University of Technology.
Craigie, M, Osseiran-Moisson, R, Hemsworth, D, Aoun, S, Francis, K, Brown, J, Hegney, D & Rees, C 2016, 'The influence of trait-negative affect and compassion satisfaction on compassion fatigue in Australian nurses', *Psychological Trauma: Theory, Research, Practice and Policy*, vol. 8, no. 1, pp. 88-97.
Creswell, J, Fetters, M & Ivankova, N 2004, 'Designing a mixed methods study in primary care', *Annals of Family Medicine*, vol. 2, no. 1, pp. 7-12.
Creswell, J, Klassen, A, Plano Clark, V & Clegg Smith, K 2010, *'Best practices for mixed methods research in the health sciences', in*, Office of Behavioral and Social Science Research,National Institute of Health USA
Creswell, J. W. (2014). Research Design: Qualitative, Quantitative and Mixed Methods Approaches (4th ed.). London: Sage Publications Ltd.
Curran, J, Cassidy C, Chiasson, D, MacPhee S & Bishop, A 2017, 'Patient and caregiver expectations of emergency department care: A scoping literature review', *International Emergency Nursing* vol. 32, pp. 62-69.
Curtis, J, Ciechanowski, P, Downey, L, Gold, J, Nielsen, E, Shannon, S, Treece, P, Young, J & Engelberg, R 2012, 'Development and evaluation of an interprofessional communication intervention to improve family outcomes in the ICU', *Contemporary Clinical Trials*, vol. 33, no. 6, pp. 1245-1254.
Curtis, J, Sprung, C & Azoulay, E 2014, 'The importance of word choice in the care of critically ill patients and their families', *Intensive Care Medicine*, vol. 40, pp. 606-608.
Cuthbertson, B, Roughton, S, Jenkinson, D, MacLennan G & Vale, L 2010, 'Quality of life in the five years after intensive care: a cohort study', *Critical Care*, vol. 14, p. 1-12. doi: 10.1186/cc8848
Cuthbertson, B, Francis, J, Campbell, M, MacIntyre, L, Seppelt, I & Grimshaw, J 2010, 'A study of the perceived risks, benefits and barriers to the use of SDD in adult critical care units (The SuDDICU study)', *Trials*, vol. 11, pp. 117-117.
Damboise, C & Cardin, S 2003, 'Family-centred critical-care: how one unit implemented a plan', *American Journal of Nursing*, vol. 103, no. 6, pp. 56AA-56EE.
Davidson, J 2009, 'Family-centered care: meeting the needs of patients' families and helping families adapt to critical illness', *Critical Care Nurse*, vol. 29, no. 3, pp. 28-34.
Davidson, J, Jones, C & Bienvenu, O 2012, 'Family response to critical illness: post-intensive care syndrome–family', *Critical Care Medicine*, vol. 40, no. 2, pp. 618-624.
Davidson, J, Powers, K, Hedayat, K, Tieszen, M, Kon, A, Shepard, E, Spuhler, V, Todres, I, Levy, M, Barr, J, Ghandi, R, Hirsch, G & Armstrong, D 2007, 'Clinical practice

guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004-2005', *Critical Care Medicine*, vol. 35, no. 2, pp. 605-22.
Davidson, J, Savidan, K, Barker, N, Ekno, M, Warmuth, D & Degen-De Cort, A 2014, 'Using Evidence to Overcome Obstacles to Family Presence', *Critical Care Nursing Quarterly*, vol. 37, no. 4, pp. 407-421.
Debono, D 2014, Learning the rules of the game: how 'good nurses' negotiate workarounds, doctoral thesis, University of Tasmania.
Denehy, L, Skinner, E, Edbrooke, L, Haines, K, Warrillow, S, Hawthorne, G, Gough, K, Vander Hoorn, S, Morris, M & Berney, S 2013, 'Exercise rehabilitation for patients with critical illness: a randomized controlled trial with 12 months of follow-up', *Critical Care* vol. 17, pp. 1-12.
Donabedian, A 1988, 'The quality of care. How can it be assessed?' *Journal of the American Medical Association*, vol. 260, no. 12, pp. 1743-1748.
Duffield, C, Roche, M, Homer, C, Buchan, J & Dimitrelis, S 2014, 'A comparative review of nurse turnover rates and costs across countries', *Journal of Advanced Nursing*, vol. 70, no. 12, pp. 2703-2712.
du Prel, J.-B, Röhrig, B, Hommel, G & Blettner, M 2010, 'Choosing statistical tests: part 12 of a series on evaluation of scientific publications', *Deutsches Arzteblatt International*, vol. 107, no. 19, pp. 343-348.
Efstathiou, N & Clifford, C 2011, 'The critical care nurse's role in end-of-life care: issues and challenges', *Nursing in Critical Care*, vol. 16, no. 3, pp. 116-23.
Eggenberger, S & Nelms, T 2007, 'Being family: the family experience when an adult member is hospitalized with a critical illness', *Journal of Clinical Nursing*, vol. 16, no. 9, pp. 1618-28.
Embriaco, N, Azoulay, E, Barrau, K, Kentish-Barnes, N, Pochard, F, Loundou, A & Papazian, L 2007, 'High level of burnout in intensivists: prevalence and associated factors', *American Journal Respiratory Critical Care Medicine*, vol. 175, no. 11, pp. 686-692.
Engel, H, Tatebe, S, Alonzo, P, Mustille, R & Rivera, M 2013, 'Physical therapist–established intensive care unit early mobilization program: quality improvement project for critical care at the University of California San Francisco Medical Center', *Physical Therapy*, vol. 93, no. 7, p. 975.
Ermakova, T, Fabian, B & Zarnekow, R 2016, 'Improving individual acceptance of health clouds through confidentiality assurance', *Applied Clinical Informatics Journal*, vol. 7, no. 4, pp. 983–993.
Fan, E, Cheek, F, Chlan, L, Gosselink, R, Hart, N, Herridge, M, Hopkins, R, Hough, C, Kress, J, Latronico, N, Moss, M, Needham, D, Rich, M, Stevens, R, Wilson, K, Winkelman, C, Zochodne, D & Ali, N 2014, 'An official American Thoracic Society clinical practice guideline: The diagnosis of Intensive Care Unit–acquired weakness in adults', *American Journal of Respiratory and Critical Care Medicine*, vol. 190, no. 12, pp. 1437-1446.
Fereday, J 2006, 'Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development', *International Journal of Qualitative Methods*, pp. 80-92.
Fetters, M, Curry, L & Creswell, J 2013, 'Achieving integration in mixed methods designs principles and practices', *Health Services Research*, vol. 48, no. 6, pp. 2134-2156.
Fetters, M & Molina-Azorin, J 2017, 'The Journal of Mixed Methods Research starts a new decade: the mixed methods research integration trilogy and its dimensions', *Journal of Mixed Methods Research*, vol. 11, no. 3, pp. 291-307.

Fincham, J 2008, 'Response rates and responsiveness for surveys, standards, and the journal', *American Journal of Pharamceutical Education,* vol. 72, no. 2, p. 43.
Flinkman, M, Leino-Kilpi, H & Salanterä, S 2010, 'Nurses' intention to leave the profession: integrative review', *Journal of Advanced Nursing,* vol. 66, no. 7, pp. 1422-1434.
French, S, Lenton, R., Walters, V & Eyles, J 2000, 'An empirical evaluation of an expanded Nursing Stress Scale ', *Journal of Nursing Management,* vol. 8, no. 2, pp. 161-178.
Fricker, R 2008, *The Sage Handbook of Online Research Methods,* viewed 21 December 2018,http://faculty.nps.edu/rdfricke/docs/5123-fielding-ch11.pdf
Garrouste-Orgeas, M, Willems, V, Timsit, J.-F, Diaw, F, Brochon, S, Vesin, A, Philippart, F, Tabah, A, Coquet, I, Bruel, C, Moulard, M.-L, Carlet, J & Misset, B 2010, 'Opinions of families, staff, and patients about family participation in care in intensive care units', *Journal of Critical Care,* vol. 25, no. 4, pp. 634-640.
Gentry, S, McArthur, R, Millegan, J, Morris-White, E, Scott, S & Williams, L 2014, 'A study to evaluate the needs of family members of critically ill patients in the ICU', *Journal of Undergraduate Research La Grange College,* vol. 11.
Goldfarb, M, Bibas, L, Bartlett, V, Jones, H & Khan, N 2017, 'Outcomes of patient- and family-centered care interventions in the ICU: A systematic review and meta-analysis', *Critical Care Medicine,* vol. 45, no. 10, pp. 1751-1761.
Gray-Toft, P & Anderson, G 1981a, 'Stress amongst hospital nursing staff; its causes and effects', *Social Science and Medicine,* vol. 15A, pp. 639-647.
Gray-Toft, P & Anderson, J 1981b, 'The Nursing Stress Scale: development of an instrument', *Journal of Behavioral Assessment,* vol. 3, no. 1, pp. 11-23.
Gray-Toft, P & Anderson, J 1985, 'Organizational stress in the hospital: development of a model for diagnosis and prediction', *Health Services Research,* vol. 19, no. 6(1), pp. 753-774.
Green, M, Marzano, V, Leditschke, I, Mitchell, I & Bissett, B 2016, 'Mobilization of intensive care patients: a multidisciplinary practical guide for clinicians', *Journal of Multidiscipilinary Healthcare,* vol. 9, pp. 247-56.
Greenfield, D, Nugus, P, Travaglia, J & Braithwaite, J 2010, 'Auditing an organisations' interprofessional learning and interprofessional practice: the interprofessional praxis audit framework (IPAF)', *Journal of Interprofessional Care,* vol. 24, no. 4, pp. 436-449.
Griffiths, P 2009, 'Staffing levels and patient outcomes', *Nursing Management UK,* vol. 16, no. 6, pp. 22-23.
Griffiths, R & Hall, J 2010, 'Intensive care unit-acquired weakness', *Critical Care Medicine,* vol. 38, no. 3, pp. 779-787.
Griffiths, J, Hatch, R, Bishop, J, Morgan, K, Jenkinson, C, Cuthbertson, B, & Brett, S 2013, 'An exploration of social and economic outcome and associated health-related quality of life after critical illness in general intensive care unit survivors: a 12-month follow-up study', *Critical Care,* vol. 17, no. 3, p. R100.
Gruenberg, D, Shelton, W, Rose, S, Rutter, A, Socaris, S & McGee, G 2006, 'Factors influencing length of stay in the intensive care unit ', *American Journal of Critical Care,* vol. 15, no. 5, pp. 502-509.
Gruther, W, Benesch, T, Zorn, C, Paternostro-Sluga, T, Quittan, M, Fialka-Moser, V, Spiss, C, Kainburger, F & Crevenna, R 2008, 'Muscle wasting in intensive care unit patients: ultrasound observation of the M. quadriceps femoris muscle layer', *Journal of Rehabilitation Medicine,* vol. 40, pp. 185-189.
Gurses, A & Carayon, P 2009, 'Exploring performance obstacles of intensive care nurses', *Applied Ergonomics,* vol. 40, no. 3, pp. 509-518.

Gurses, A, Carayon, P & Wall, M 2009, 'Impact of performance obstacles on intensive care nurses' workload, perceived quality and safety of care, and quality of working life.', *Health Service Research,* vol. 2, no. 1, pp. 422-443.

Hall, L, Johnson, J, Watt, I, Tsipa, A & O'Connor, D 2016, 'Healthcare staff wellbeing, burnout, and patient safety: a systematic review', *PLOS ONE,* vol. 11, no. 7, p. e0159015, viewed 25 May 2019, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4938539/

Hardin, S 2012, 'Engaging families to participate in care of older critical care patients', *Critical Care Nurse,* vol. 32, no. 3, p. 35.

Harris, P, Taylor, R, Thiekle, R, Payne, J, Gonzales, N & Conde, J 2009, 'Research electronic data capture (REDCap)- A metadata-driven methodology and workflow process for providing translational research informatics support', *Journal of Biomedical Informatics,* vol. 42, no. 2, p. 377--381.

Hayes, B, Douglas, C & Bonner, A 2013, 'Work environment, job satisfaction, stress and burnout among haemodialysis nurses', *Journal of Nursing Management,* vol. 23, pp. 588-598.

Healy, C & McKay, M 1999, 'Identifying sources of stress and job satisfaction in the nursing environment', *Australian Journal of Advanced Nursing,* vol. 17, no. 2, pp. 30-35.

Healy, C & McKay, M 2000, 'Nursing stress: the effects of coping strategies and job satisfaction in a sample of Australian nurses', *Australian Journal of Advanced Nursing,* vol. 31, no. 3, pp. 681-8.

Hegney, D, Craigie, M, Hemsworth, D, Osseiran-Moisson, R, Aoun, S, Francis, K & Drury, V 2014, 'Compassion satisfaction, compassion fatigue, anxiety, depression and stress in registered nurses in Australia: study 1 results', *Journal of Nursing Management,* vol. 22, no. 4, pp. 506-518.

Henneman, E & Cardin, S 2002, 'Family centred care: a practical approach to making it happen', *Critical Care Nurse,* vol. 22, no. 6, pp. 12-19.

Herridge, M 2009, 'Building consensus on ICU-acquired weakness', *Intensive Care Medicine,* vol. 35, no. 1, pp. 1-3.

Herridge, M 2011, 'Recovery and long-term outcome in acute respiratory distress syndrome', *Critical Care Clinics,* vol. 27, no. 3, pp. 685-704.

Hetland, B, Hickman, R, McAndrew, N & Daly, B 2017, 'Factors influencing active family engagement in care among critical care nurses', *AACN Advanced Critical Care,* vol. 28, no. 2, pp. 160-170.

Hetland, B, McAndrew, N, Perazzo, J & Hickman, R 2018, 'A qualitative study of factors that influence active family involvement with patient care in the ICU: survey of critical care nurses', *Intensive and Critical Care Nursing,* vol. 44, pp. 67-75.

Hinkle, J, Fitzpatrick, E & Oskrochi, R 2011, 'Needs of American relatives of intensive care patients: perceptions of relatives, physicians and nurses', *Intensive Critical Care Nursing,* vol. 27, no. 4, pp. 218-25.

Hodgson, C & Tipping, C 2017, 'Physiotherapy management of intensive care unit-acquired weakness', *Journal of Physiotherapy,* vol. 63, pp. 4-10.

Hoonakker, P, Carayon, P, Gurses, A, Brown, R, McGuire, K, Khunlertkit, A & Walker, J 2011, 'Measuring workload of ICU nurses witha questionnaire survey: The NASA task load index (TLX)', *IIE Transactions on Healthcare Systems Engineering,* vol. 1, no. 2, pp. 131-143.

Illawarra Shoalhaven Local Health Disctrict 2013, *Step by step writing guide for developing plain English consumer information,* viewed 3 March 2015, http://www.cec.health.nsw.gov.au/__data/assets/pdf_file/0007/259072/islhdstepbystepplainenglishwritingguideforconsumerinformation.pdf

Institute for Healthcare Improvement, viewed 25 May 2015, http://www.ihi.org/
Institute of Medicine (IOM) 2001, *'Crossing the Quality Chasm (2001) A new health system for the 21st Century'* viewed May 2014, https://www.ncbi.nlm.nih.gov/books/NBK222271/ Susman library
Institute for Patient and Family-Centred Care, viewed 25 May 2015, http://www.ipfcc.org/
Jacob, M, Horton, C, Rance-Ashley, S, Field, T, Patterson, R, Johnson, C, Saunders, H, Shelton, T, Miller, J & Frobos, C 2016, 'Needs of patients' family members in an intensive care unit with continuous visitation', *American Journal of Critical Care,* vol. 25, no. 2, pp. 118-125.
Johnson, B, Abraham, M & Shelton, T 2009, 'Patient and family-centred care: Partnerships for quality and safety', *North Carolina Medical Journal,* vol. 70, no. 2, pp. 125-130.
Jolley, S, Bunnell, A & Hough, C 2016, 'ICU-acquired weakness', *Chest,* vol. 150, no. 5, pp. 1129-1140.
Jones, N, Wieschhaus, K, Martin, B & Tonino, P 2019, 'Medical supervision of high school athletics in Chicago: a follow-up study', *Orthopaedic Journal of Sports Medicine,* vol. 7, no. 8, pp. 2325967119862503-2325967119862503, viewed 13 September 2019, doi.10.1177/2325967119862503
Kaiser, K 2009, 'Protecting respondent confidentiality in qualitative research', *Qualitative Health Research,* vol. 19, no. 11, pp. 1632-1641.
Kean, S & Mitchell, M 2014, 'How do intensive care nurses perceive families in intensive care? Insights from the United Kingdom and Australia', *Journal of Clinical Nursing,* vol. 23, no. 5-6, pp. 663-72.
Keenan, A & Joseph, L 2010 'The needs of family members of severe traumatic brain injured patients during critical and acute care: a qualitative study', *Canadian Journal of Neuroscience Nursing,* vol. 3, pp. 25-35.
Kentish-Barnes, N, McAdam, J, Kouki, S, Cohen-Solal, Z, Chaize, M, Galon, M, Souppart, V, Puntillo, K & Azoulay, E 2015, 'Research participation for bereaved family members: experience and insights from a qualitative study', *Critical Care Medicine,* vol. 43, no. 9, pp. 1839-1845.
Kentish-Barnes, N, Chevret, S & Azoulay, E 2018, 'Guiding intensive care physicians communication and behavior towards bereaved relatives: study protocol for a cluster randomized controlled trial (COSMIC-EOL)', *Trials,* vol. 19, no. 1, p. 698.
Khandkar S 2009 'Open coding' viewed 19 May 2019 http://pages.cpsc.ucalgary.ca/~saul/wiki/uploads/CPSC681/open-coding.pdf
Kho, M, Needham, D, Truong, A, Brower, R, Palmer, J, Fan, E, Zanni, J, Ciesla, N, Feldman, D & Korupolu, R 2012, 'Neuromuscular electrical stimulation for intensive care unit-acquired weakness: protocol and methodological implications for a randomized, sham-controlled, phase II trial', *Physical Therapy,* vol. 92, no. 12, pp. 1564-1579.
Kho, M, Molloy, A, Clarke, F, Ajami, D, McCaughan, M, Obrovac, K, Murphy, C, Camposilvan, L, Herridge, M, Koo, K, Rudkowski, J, Seely, A, Zanni, J, Mourtzakis, M, Piraino, T & Cook, D 2016, 'TryCYCLE: A prospective study of the safety and feasibility of early in-bed cycling in mechanically ventilated patients', *PLoS One,* vol. 11, no. 12, p. e0167561.
Kinrade, T, Jackson, A & Tomnay, J 2010, 'The psychosocial needs of families during critical illness: comparison of nurses' and family members' perspectives', *Australian Journal of Advanced Nursing,* vol. 27, no. 1, pp. 82-88.
Kitson, A, Marshall, A, Bassett, K & Zeitz, K 2013, 'What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing ', *Journal of Advanced Nursing,* vol. 69, no. 1, pp. 4-15.

Knaus, WA, Draper, EA, Wagner, DP & Zimmerman, JE 1985, 'APACHE II: a severity of disease classification system', *Critical Care Medicine,* vol. 13, no. 10, pp. 818-829.
Kompanje, E, Piers, R & Benoit, D 2013, 'Review causes and consequences of disproportionate care in intensive care medicine', *Current Opinion in Critical Care,* vol. 19, no. 6, pp. 630-635.
Kosco, M & Warren, N 2000, 'Critical care nurses' perceptions of family needs as met.', *Critical Care Nursing Quarterly,* vol. 23, no. 2, pp. 60-72.
Kotter, J 1996, *Leading Change*, Harvard Business School Press, Boston, MA 2012 Kindle edition, viewed 14 July 2018.
Kress, J & Hall, J 2014, 'ICU-acquired weakness and recovery from critical illness', *The New England Journal of Medicine,* vol. 370, no. 17, p. 1626.
Kress, J & Herridge, M 2012, 'Medical and economic implications of physical disability of survivorship', *Seminars in Respiratory and Critical Care Medicine,* vol. 33
Kuster, A 2017,*Analysis of Likert data,* online video, viewed 18 December 2019, https://www.youtube.com/watch?v=7m3929CJvcM
Lakanmaa, R, Suominen, T, Ritmala-Castrén, M, Vahlberg, T & Leino-Kilpi, H 2015, 'Basic competence of intensive care unit nurses: cross-sectional survey study,' *Biomed Research International,* Volume 2015, Article ID 536724, 12 pages, viewed 1 August 2019, http://dx.doi.org/10.1155/2015/536724
Lam, P & Beaulieu, M 2004, 'Experiences of families in the neurological ICU: A "bedside phenomenon"', *Journal of Neuroscience Nursing,* vol. 36, no. 3, pp. 145-159.
Lee, M, Friedenberg, A, Mukpo, D, Conray, K & Palmisciano A 2007, 'Visiting hours policies in New England intensive care units: strategies for improvement', *Critical Care Medicine,* vol. 35, no. 2, pp. 497-501.
Lee, M, Holzemer, W & Faucett, J 2007, 'Psychometric evaluation of the Nursing Stress Scale (NSS) among Chinese nurses in Taiwan', *Journal of Nursing Measurement,* vol. 15, no. 2, pp. 133-44.
Leiter, M & Maslach, C 2016, 'Latent burnout profiles: A new approach to understanding the burnout experience', *Burnout Research,* vol. 3, no. 4, pp. 89-100.
Leske, J 1991, 'Internal pyschometric properties of the Critical Care Family Needs Inventory', *Heart and Lung,* vol. 20, no. 3, pp. 236-244.
Leske, J 1998, 'Interventions to decrease family anxiety', *Critical Care Nurse,* vol. 18, no. 4, pp. 92-95.
Leske, J 2002, 'Interventions to decrease family anxiety', *Critical Care Nurse,* vol. 22, no. 6, p. 61.
Lilly, C, Cody, S, Zhao, H, Landry, K, Baker, S, McIlwaine, J, Chandler, M & Irwin, R 2011, 'Hospital mortality, length of stay, and preventable complications among critically ill patients before and after tele-ICU reengineering of critical care processes', *Journal of the American Medical Association,* vol. 305, no. 21, pp. 2175-2183.
Lim, J, Bogossian, F & Ahern, K 2010, 'Stress and coping in Australian nurses: a systematic review', *International Nursing Review,* vol. 57, pp. 22-31.
Lin, W, Halpern, S, Prasad Kerlin, M & Small, D 2017, 'A "placement of death" approach for studies of treatment effects on ICU length of stay', *Statistical Methods in Medical Research,* vol. 26, no. 1, pp. 292-311.
Lincoln, Y. & Guba, E. 1985, *Naturalistic Inquiry*, Sage Publications, California.

Lunenberg, F 2010, 'Approaches to managing organizational change', *International Journal of Scholarly Academic Intellectual Diversity,* vol. 12, no. 1
Luxford, K & Newell, S 2015, 'New South Wales mounts “patient based care” challenge', *British Medical Journal,* vol. 350:g7582.

Mackie, B, Mitchell, M & Marshall, A 2016, 'The impact of interventions that promote family involvement in care on adult acute-care wards: An integrative review', *Collegian*, vol. 25, pp. 131-140.
Marti, J, Hall, P, Hamilton, P, Lamb, S, McCabe, C, Lall, R, Darbyshire, J, Young, D & Hulme, C 2016, 'One-year resource utilisation, costs and quality of life in patients with acute respiratory distress syndrome (ARDS): secondary analysis of a randomised controlled trial', *Journal of Intensive Care*, vol. 4, no. 1, p. 56.
Maslach, C & Jackson, S 1981, 'The measurement of experienced burnout', *Journal of Organiszational Behavior*, vol. 2, no. 2
Matis, G & Birbilis, T 2008, 'The Glasgow Coma Scale a brief review: past, present, future. '*Acta Neurologica Belgica* vol. 108, no. 3, pp. 75-89.
Maxwell, K, Stuenkel, D & Saylor, C 2007, 'Needs of family members of critically ill patients: A comparison of nurse and family perceptions', *Heart & Lung*, vol. 36, no. 5, pp. 367-376.
Mays, N & Pope, C 2000, 'Qualitative research in health care: Assessing quality in qualitative research', *British Medical Journal*, vol. 320, no. 7226, pp. 50-52.
McAdam, J, Arai, S & Puntillo, K 2008, 'Unrecognized contributions of families in the intensive care unit', *Intensive Care Medicine*, vol. 34, pp. 1097-1101.
McCarthy, V, Power, S & Greiner, B 2010, 'Perceived occupational stress in nurses working in Ireland', *Occupational Medicine*, vol. 60, no. 8, pp. 604-610.
McCormack, B, Karlsson, B, Dewing, J & Lerdal, A 2010, 'Exploring person-centredness: a qualitative meta-synthesis of four studies', *Scandinavian Journal of Caring Sciences*, vol. 24, pp. 620-634.
McCormack, B & McCance, T 2006, 'Development of a framework for person-centred nursing', *Journal of Advanced Nursing*, vol. 56, no. 5, pp. 472-479.
McCance, T, McCormack, B & Dewing, J 2011, 'An exploration of person-centredness in practice', *Online Journal Issues in Nursing*, vol. 16, no. 2, p. 1.
McCance, T, Slater, P & McCormack, B 2009, 'Using the caring dimensions inventory as an indicator of person-centred nursing', *Journal of Clinical Nursing*, vol. 18, no. 3, pp. 409-417.
McLaws, M & Jarvis, W 2014, 'Central line-associated bloodstream infection (CLABSI) rates: achieving the elusive goal of zero', *Healthcare Infection*, vol. 19, pp. 39-41.
Meterko, M, Wright, S, Lin, H, Lowy, E & Cleary, P 2010, 'Mortality among patients with acute myocardial infarction; the influences of patient-centred care and evidence-based medicine', *Health Service Research*, vol. 45, no. 5, pp. 1188-1204.
Mitchell, M, Chaboyer, W, Burmeister, E & Foster, M 2009, 'Positive effects of a nursing intervention on family centred care in adult critical care', *American Journal of Critical Care*, vol. 6, pp. 543-552.
Mitchell, M & Chaboyer, W 2010, 'Family centred care--a way to connect patients, families and nurses in critical care: a qualitative study using telephone interviews', *Intensive Critical Care Nursing*, vol. 26, no. 3, pp. 154-160.
Mitchell, M , Coyer, F, Kean, S, Stone, R, Murfield, J & Dwan, T 2016, 'Patient, family-centred care interventions within the adult ICU setting: an integrative review', *Australian Critical Care*, vol. 29, no. 4, pp. 179-193.
Mitchell, M, Dwan, T, Takashima, M, Beard, K, Birgan, S, Wetzig, K & Tonge, A 2019, 'The needs of families of trauma intensive care patients: A mixed methods study', *Intensive and Critical Care Nursing*, vol. 50, pp. 11-20.
Molter, N 1979, 'Needs of relatives of critically ill patients: A descriptive study', *Heart and Lung*, vol. 8, no. 2, pp. 332-339.

Moola, S, Ehlers, V & Hattingh, S 2008, 'Critical care nurses' perceptions of stress and stress-related situations in the workplace', *Curationis*, vol. 31, no. 2, pp. 74-83, viewed 22 July 2018, doi.10.4102/curationis.v31i2.989

Morris, P, Goad, A, Thompson, C, Taylor, K, Harr, B, Passmore, L, Ross, A, Anderson, L, Baker, S, Sanchez, M, Penley, L, Howard, A, Dixon, L, Leach, S, Small, R, Hite, R & Haponik, R 2008, 'Early intensive care unit mobility therapy in the treatment of acute respiratory failure', *Critical Care Medicine,* vol. 36, no. 8, pp. 2238-2243.

Morris, P 2008, 'Early intensive care unit mobility therapy in the treatment of acute respiratory failure', *Critical Care Medicine,* vol. 36, no. 8, pp. 2238-2243.

Moss, M, Nordon-Craft, A & Malone, D 2016, 'A randomized trial of an intensive physical therapy program for patients with acute respiratory failure', *American Journal of Respiratory and Critical Care Medicine,* vol. 193, no.10,pp.1101-1110.

Nahm, F 2016, 'Nonparametric statistical tests for the continuous data: the basic concept and the practical use', *Korean Journal of Anesthesiology*, vol. 69, no. 1, pp. 8-14.

Naidoo, V & Sibiya, M 2014, 'Experiences of critical care nurses of death and dying in an Intensive Care Unit: A phenomenological study', *Journal of Nursing*, vol. 3, no. 4

National Health Service (NHS) 2012, *'The NHS friends and family test. Implementation guidance'*, viewed 25 May 2014, https://www.england.nhs.uk/fft/fft-guidance/

National Health Service (NHS) England 2014, *'Review of the Friends and Family Test'*, viewed 4 September 2018, https://www.england.nhs.uk/fft/fft-test-review/

Needham, D, Davidson, J, Cohen, H, Hopkins, R, Weinert, C, Wunsch, H, Zawistowski, C, Bemis-Dougherty, A, Berney, S, Bienvenu, O, Brady, S, Brodsky, M, Denehy, L, Elliott, D, Flatley, C, Harabin, A, Jones, C, Louis, D, Meltzer, W, Muldoon, S, Palmer, J, Perme, C, Robinson, M, Schmidt, D, Scruth, E, Spill, G, Storey, C, Render, M, Votto, J & Harvey, M 2012, 'Improving long-term outcomes after discharge from intensive care unit: Report from a stakeholders' conference', *Critical Care Medicine,* vol. 40, no. 2, pp. 502-509.

Negrini, D, Sheppard, L, Mills, G, Jacobs, P, Rapoport, J, Bourne, R, Guidet, B, Cosmos, A, Prien, T, Anderson, G & Edbrooke, D 2006, 'International programme for resource use in critical care (IPOC) – a methodology and initial results of cost and provision in four European countries', *Acta Anaesthesiologica Scandinavica,* vol. 50, no. 1, pp. 72-79.

Nelson, T 2009, Stress levels and sources of occupational stress among Psi Ch faculty advisors, Honors thesis, Utah State University, viewed 30 August 2017, https://pdfs.semanticscholar.org/7e3d/2d7872257b759c8bf24203ee2079e7e956b1.pdf

Nelson, J, Puntillo, K, Pronovost, P, Walker, A, McAdam, J, Ilaoa, D & Penrod, J 2010, 'In their own words: Patients and families define high-quality palliative care in the intensive care unit', *Critical Care Medicine*, vol. 38, no. 3, pp. 808–818.

Nickels, M, Aitken, L, Walsham, J, Barnett, A & McPhail, S 2017, 'Critical care cycling study (CYCLIST) trial protocol: a randomised controlled trial of usual care plus additional in-bed cycling sessions versus usual care in the critically ill', *British Medical Journal open,* vol. 7, no. 10, pp. e017393-e017393, doi: 10.1136/bmjopen-2017-017393.

Nixon, A, Mazzola, J, Bauer, J, Krueger, J & Spector, P 2011, 'Can work make you sick? A meta-analysis of the relationships between job stressors and physical symptoms', *Work & Stress,* vol. 25, no. 1, pp. 1-22.

Noble, H & Smith, J 2015, 'Issues of validity and reliability in qualitative research', *Evidence Based Nursing*, vol. 18, no. 2, pp. 34-35.

Nolen, K & Warren, N 2014, 'Meeting the needs of family members of ICU patients', *Critical Care Nursing Quarterly*, vol. 37, no. 4, pp. 393-406.

Nulty, D 2008, 'The adequacy of response rates to online and paper surveys: what can be done?', *Assessment and Evaluation in Higher Education*, vol. 33, no. 3, pp. 301-314.
Nyumba, T, Wilson, K, Derrick, C & Mukherjee, N. 2017, 'The use of focus group discussion methodology: Insights from two decades of application in conservation', *Methods in Ecology and Evolution*, vol. 9, pp. 20-32.
O'Connor, E & Walsham, J 2009, 'Should we mobilise critically ill patients? A review', *Critical Care and Resuscitation*, vol. 11, no. 4, pp. 290-300.
Ogden, K, Barr, J & Greenfield, D 2017, 'Determining requirements for patient-centred care: a participatory concept mapping study', *BMC Health Services Research*, vol. 17, no. 1, pp. 780-780.
Olding, M, McMillan, S, Reeves, S, Schmitt, M, Puntillo, K & Kitto, S 2016, 'Patient and family involvement in adult critical and intensive care settings: a scoping review', *Health Expectations*, vol. 19, no. 6, pp. 1183-1202.
O'Neill-Norris, L & Grove, S 1986, ' Investigation of selected psychosocial needs of family members of critically ill patients', *Heart and Lung*, vol. 15, no. 2, pp. 194-199.
Obringer, K, Hilgenberg, C & Booker, K 2012, 'Needs of adult family members of intensive care unit patients: Needs of adult family members', *Journal of Clinical Nursing*, vol. 21, no. 11-12, pp. 1651-1658.
Olding, M, McMillan, S, Reeves, S, Schmitt, M, Puntillo, K & Kitto, S 2016, 'Patient and family involvement in adult critical and intensive care settings: a scoping review', *Health Expectations*, vol. 19, no. 6, pp. 1183-1202.
Onwuegbuzie, A & Collins, K 2007, 'A typology of mixed methods sampling designs in social science research', *The Qualitative Report*, vol. 12, no. 2, pp. 281-316.
Onwuegbuzie, A, Dickinson, W, Leech, N & Zoran, A 2009, 'A qualitative framework for collecting and analyzing data in focus group research', *International Journal of Qualitative Methods*, vol. 8, no. 3, pp. 1-21.
Page, K, Barnett, A & Graves, N 2017, 'What is a hospital bed day worth? A contingent valuation study of hospital chief executive officers', *BMC Health Services Research*, vol. 17, no. 1, p. 137.
Pathak, V, Chakraborty, T & Mukhopadhyay, S 2013, 'Reliability and validity analysis of modified Nursing Stress Scale for Indian population', *Journal of Nurs Measurement*, vol. 21, no. 2, pp. 224-45.
Pastores, S, Dakwar, J & Halpern, N 2012, 'Costs of critical care medicine', *Critical Care Clinics*, vol. 28, no. 1, pp. 1-10.
Picker Institute 2008, *'Patient Centred Care Improvement Guide'*, viewed 14 March 2014. https://www.pickerinstitute.org
Picker Institute 2014, *NHS Friends and Family Test "unreliable" comparison tool says Picker*, viewed 20 January 2020 https://www.picker.org/news/nhs-friends-family-test-unreliable-comparison-tool-says-picker-institute-europe/
Skillen, J. 2019, 'The Friends and Family Test: From card sorts to control charts', *Methodological Innovations*, pp. 1-7.
Polit, D & Beck, C 2010 *Essentials of Nursing Research* (7th ed.) China: Wolter Kluwer Health, Lippincott Williams & Wilkins.
Poncet, M, Touillic, P, Papazian, L, Kentish-Barnes, N, Timsit, J, Pochard, F, Chevret, S, Schlemmer, B & Azoulay, E 2007, 'Burnout syndrome in critical care nursing', *American Journal of Respiratory and Critical Care Medicine*, vol. 175, pp. 698-704.
Proch, R 2011, 'Creating a culture of patient and family centred care', *John Hopkins Nursing Magazine*,viewed 24 November 2013, http://magazine.nursing.jhu.edu/2011/12/family-matters-2

Purcell, S, Kutash, M & Cobb, S 2011, 'The relationship between nurses' stress and nurse staffing factors in a hospital setting', *Journal of Nursing Management*, vol. 19, pp. 714-720.
Rapoport, J, Teres, D, Zhao, Y & Lemeshow, S 2003, 'Length of stay data as a guide to hospital economic performance for ICU patients', *Medical Care*, vol. 41, no. 3, pp. 386-97.
Rathert, C, Williams, E, McCaughey, D & Ishqaidef, G 2015, 'Patient perceptions of patient-centred care: empirical test of a theoretical model', *Health Expectations*, vol. 18, no. 2, pp. 199-209.
Rathert, C, Wyrwich, M & Boren, S 2012, 'Patient-centered care and outcomes: a systematic review of the literature', *Medical Care Research and Review*, vol. 70, no. 4, pp. 351-379.
Rechner, I & Lipman, J 2005, 'The costs of caring for patients in a tertiary referral Australian Intensive Care Unit', *Anaesthesia and Intensive Care*, vol. 33, no. 4, pp. 477-82.
REDCap, is brought to you by the Clinical Research Centre at Sydney Local Health District
Riley, B, White, J, Graham, S & Alexandrov, A 2014, 'Traditional restrictive v. patient-centred intensive cae unit visitation: perceptions of patients', family members, physicians and nurses', *American Journal of Critical Care*, vol. 23, no. 4, pp. 316-325.
Rippin, A, Zimring, C, Samuels, O & Denham, M 2015, 'Finding a middle ground: exploring the impact of patient- and family-centered design on nurse-family interactions in the neuro ICU', *Herd*, vol. 9, no. 1, pp. 80-98.
Robert, G, Cornwell, J & Black, N 2018, 'Friends and family test should no longer be mandatory', *British Medical Journal*, p. k367, viewed July 2017, doi:10.1136/bmj.k367
Roberti, S & Fitzpatrick, J 2010, 'Assessing family satisfaction with care of critically ill patients: a pilot study', *Critical Care Nurse*, vol. 30, no. 6, pp. 18-26.
Roche, M, Duffield, C, Homer, C, Buchan, J & Dimitrelis, S 2014, 'The rate and cost of nurse turnover in Australia', *Collegian*, viewed July 2017, doi:10.1016/j.colegn.2014.05.002
Rodriguez, P, Setten, M, Maskin, L, Bonelli, I, Vidomlansky, S, Attie, S, Frosiani, S, Kozima, S & Valentini, R 2012, 'Muscle weakness in septic patients requiring mechanical ventilation: Protective effect of transcutaneous neuromuscular electrical stimulation', *Journal of Critical Care*, vol. 27, no. 3, pp. 319.e1-319.e8.
Roland, P, Russell, J, Richards, K & Sullivan, S 2001, ' Visitation in critical care: Processes and outcomes of a performance improvement initiative', *Journal of Nursing Care Quality*, vol. 15, no. 2, pp. 18-26.
Rolf, M 1999, Acute care nursing: are perceived work stressors different for nurses working in critical care and non-critical?', Masters theses, Grand Valley State University, Michigan.
Rose, L & Presneill, J 2011, 'Clinical prediction of weaning and extubation in Australian and New Zealand intensive care units', *Anaesthesia and Intensive Care Journal*, vol. 39, no. 4, pp. 623-9.
Rothmann, S, van der Colff, J & Rothmann, J 2006, 'Occupational stress of nurses in South Africa', *Curationis*, vol. 29, no. 2, viewed 28 August 2019, https://pdfs.semanticscholar.org/1672/212d6beace059490ff0a4e37281c27034ed2.pdf
Rothstein, M 2010, 'Is de-identification sufficient to protect health privacy in research?', *American Journal of Bioethics*, vol. 10, no. 9, pp. 3-11.
Royal Prince Alfred Hospital (RPAH) '*Strategic Plan 2013-18'*, viewed May 2016, https://www.slhd.nsw.gov.au/pdfs/RPA_StrategicPlan.pdf

Rukstele, C & Gagnon, M 2013, 'Making strides in preventing ICU-acquired weakness: involving family in early progressive mobility', *Critical Care Nursing Quarterly*, vol. 36, no. 1, p. 141.
Schleyer, A & Curtis, J 2013, 'Family satisfaction in the ICU: why should ICU clinicians care?', *Intensive Care Medicine*, vol. 39, no. 6, pp. 1143-1145.
Schryen, G. 2015, 'Writing qualitative information systems literature reviews—guidelines for synthesis, interpretation, and guidance of research', *Communications of the Association for Information Systems*, vol. 37, pp. 286-325.
Schubart, J, Wojnar, M, Dillard, J, Meczkowski, E, Kanaskie, M, Blackall, G, Sperry, N & Lloyd, T 2015, 'ICU family communication and health care professionals: A qualitative analysis of perspectives', *Intensive and Critical Care Nursing*, vol. 31, pp. 315-321.
Schultz, M , Dunser, M, Dondorp, A, Adhikari, N, Iyer, S, Kwizera, A, Lubell, Y, Papali, A, Pisani, L, Riviello, B, Angus, D, Azevedo, L, Baker, T, Diaz, J, Festic, E, Haniffa, R, Jawa, R, Jacob, S, Kissoon, N, Lodha, R, Martin-Loeches, I, Lundeg, G, Misango, D, Mer, M, Mohanty, S, Murthy, S, Musa, N, Nakibuuka, J, Serpa Neto, A, Nguyen Thi Hoang, M, Nguyen Thien, B, Pattnaik, R, Phua, J, Preller, J, Povoa, P, Ranjit, S, Talmor, D, Thevanayagam, J & Thwaites, C 2017, 'Current challenges in the management of sepsis in ICUs in resource-poor settings and suggestions for the future', *Intensive Care Medicine*, vol. 43, no. 5, pp. 612-624.
Schweickert, W, Deprizio, D, Schmidt, G, Bowman, A, Barr, R, McCallister, K, Hall, J, Kress, J, Pohlman, M, Pohlman, A, Nigos, C, Pawlik, A, Esbrook, C, Spears, L, Miller, M & Franczyk, M 2009, 'Early physical and occupational therapy in mechanically ventilated, critically ill patients: a randomised controlled trial', *The Lancet*, vol. 373, no. 9678, pp. 1874-1882.
Schweickert, W & Hall, J 2007, 'ICU-acquired weakness', *Chest*, vol. 131, no. 5, pp. 1541-1549.
Scott, P, Thomson, P & Shepherd, A 2019, 'Families of patients in ICU: a scoping review of their needs and satisfaction with care', *Nursing Open*, vol. 6, no. 3, pp. 698-712 viewed 1 June 2019, doi: 10.1002/nop2.287
Shanafelt, T, Bradley, K, Wipf, J & Back, A 2002, 'Burnout and self-reported patient care in an internal medicine residency program', *Annals of Internal Medicine*, vol. 136, pp. 358-367.
Sheaffer, H 2010, 'The met and unmet needs of families of patients in the ICU and implications for social work', PhD thesis, University of Pennsylvania, viewed December 2016, http://repository.upenn.edu/edissertations_sp2
Shelton, W, Moore, C, Socaris, S, Gao, J & Dowling, J 2010, 'The effect of a family support intervention on family satisfaction, length-of-stay, and cost of care in the intensive care unit', *Critical Care Medicine*, vol. 38, pp. 1315-1320.
Shorter, M & Stayt, L 2010, 'Critical care nurses' experiences of grief in an adult intensive care unit', *Journal of Advanced Nursing*, vol. 66, no. 17, pp. 159-167.
Singer, E, Hippler, H-J & Schwarz, N 1992, 'Confidentiality assurances in surveys; reassurance or threat?', *International Journal of Public Opinion Research*, vol. 4, no. 3, pp. 256-268.
Skillen, J 2019, 'The Friends and Family Test: From card sorts to control charts', *Methodological Innovations*, pp. 1-7.
Spielberger, C & Vagg, P 1999, *Job Stress Survey*,Odessa, Florida.
Stayt, L 2009, ' Death, empathy and self preservation: the emotional labour of caring for families of the critically ill in adult intensive care', *Journal of Clinical Nursing*, vol. 18, no. 9, pp. 1267-1275.

Stellefson, M , Shuster, J, Chaney, B, Paige, S, Alber, J, Chaney, J & Sriram, P 2018, 'Web-based health information seeking and eHealth literacy among patients living with chronic obstructive pulmonary disease (COPD)', *Health Communication,* vol. 33, no. 12, pp. 1410-1424.

Stone, P, Mooney-Kane, C, Larson, E, Horan, T, Glance, L, Zwanziger, J & Dick, A 2007, 'Nurse working conditions and patient safety outcomes', *Medical Care,* vol. 45, no. 6, pp. 571-578.

Stricker, K, Cavegn, R, Takala, J & Rothen, H 2005, 'Does ICU length of stay influence quality of life?', *Acta Anaesthesiologica Scandinavica*, vol. 49, no. 7, pp. 975-83.

Stricker, K, Kimberger, O, Brunner, L & Rothen, H 2011, 'Patient satisfaction with care in the intensive care unit: can we rely on proxies?', *Acta Anaesthesiologica Scandinavica*, vol. 55, no. 2, pp. 149-156.

Suresh, P, Matthews, A & Coyne, I 2012, 'Stress and stressors in the clinical environment: a comparative study of fourth-year student nurses and newly qualified general nurses in Ireland: Stress and stressors in the clinical environment', *Journal of Clinical Nursing*, vol. 23, pp.770-779.

Sutkowi, S 1995, *A descriptive study of the needs of family members of trauma patients* masters theses, Grand Valley State University.

Taber, K. 2018, 'The use of Cronbach's alpha when developing and reporting research instruments in science education', *Research Science Education,* vol. 48, pp. 1273-1296.

Takman C & Severinsson, E 2005, 'Comparing Norwegian nurses' and physicians' perceptions of the needs of significant others in intensive care units', *Journal of Clinical Nursing*, vol. 14, no. 5, pp. 621–631.

Tan, S, Bakker, J, Hoogendoorn, M, Kapila, A, Martin, J, Pezzi, A, Pittoni, G, Spronk, P, Welte, R & Hakkaart-van Roijen, L 2012, 'Direct cost analysis of intensive care unit stay in four European countries: applying a standardized costing methodology', *Value Health,* vol. 15, no. 1, pp. 81-6.

Tanaka, L. M., Azevedo, L. C., Park, M., Schettino, G., Nassar, A. P., Rea-Neto, A., Tannous, L., de Souza-Dantas, V. C., Torelly, A., Lisboa, T., Piras, C., Carvalho, F. B., Maia Mde, O., Giannini, F. P., Machado, F. R., Dal-Pizzol, F., de Carvalho, A. G., dos Santos, R. B., Tierno, P. F., Soares, M. & Salluh, J. I. 2014, 'Early sedation and clinical outcomes of mechanically ventilated patients: a prospective multicenter cohort study', *Critical Care,* vol. 18, no. 4, p. R156.

Teasdale, G & Jennett, B 1974, 'Assessment of coma and impaired consciousness. A practical scale.', *The Lancet,* vol. 13, no. 2 (7872), pp. 81-84.

Teixeira, C, Ribeiro, O, Fonseca, A & Carvalho, A 2013, 'Burnout in intensive care units - a consideration of the possible prevalence and frequency of new risk factors: a descriptive correlational multicentre study', *BMC Anesthesiology,* vol. 13, no. 1, p. 388.

The Health Foundation 2013, *'Measuring patient experience'*,The Health Foundation, 90 Long Acre, London WC2E 9RA.

The Health Foundation 2014a, '*Helping measure person-centred care*, The Health Foundation, 90 Long Acre, London WC2E 9RA.

The Health Foundation, U. 2014b, *'Person centred care from ideas to action* ', The Health Foundation, 90 Long Acre, London WC2E 9RA.

The Health Partnership 2015, '*The state of play in person-centred care'*, viewed 2 October 2017, http://www.healthpolicypartnership.com/project/person-centred-care/

The King's Fund 2010, '*A high performing NHS- A review of progress (1997-2010)*', viewed 7 October 2017, https://www.kingsfund.org.uk/sites/default/files/high-performing-nhs-progress-review-1997-2010-ruth-thorlby-jo-maybin-kings-fund-april-2010_0.pdf

The King's Fund 2012, '*From vision to action. Making patient centred care a reality* ',viewed 7 October 2017, https://www.kingsfund.org.uk/publications/articles/vision-action-making-patient-centred-care-reality.

The King's Fund 2015, *'Patients' experiences of using hospital services'*, viewed 7 October 2017, https://www.kingsfund.org.uk/publications/patients-experience-using-hospital-services

Todaro-Franceschi, V 2013, 'Critical care nurses' perceptions of preparedness and ability to care for the dying and their professional quality of life', *Dimensions of Critical Care Nursing*, vol. 32, no. 4, pp. 184-190.

Trankle, S 2014, 'Is a good death possible in Australian critical and acute settings?: physician experiences with end-of-life care', *BMC Palliative Care*, vol. 13, no. 41, doi: 10.1186/1472-684X-13-41

Turnbull, A, Rabiee, A & Davis, W 2016, 'Outcome measurement in ICU survivorship research from 1970 to 2013: a scoping review of 425 publications', *Critical Care Medicine*, vol. 44, pp. 1267-1277.

Unroe, M, Kahn, J, Carson, S, Govert, J, Martinu, T, Sathy, S, Clay, A, Chia, J, Gray, A, Tulsky, J & Cox, C 2010, 'One-year trajectories of care and resource utilization for recipients of prolonged mechanical ventilation', *Annals of Internal Medicine*, vol. 153, no. 3, pp. 167-175.

van den Broek, J, Brunsveld-Reinders, A, Zedlitz, A, Girbes, A, de Jonge, E & Arbous, M 2015, 'Questionnaires on family satisfaction in the adult ICU: a systematic review including psychometric properties', *Critical Care Medicine*, vol. 43, no. 8, pp. 1731-1744.

van Mol, M, Kompanje, E, Benoit, D, Bakker, J & Nijkamp, M 2015, 'The prevalence of compassion fatigue and burnout among healthcare professionals in intensive care units: a systematic review', *PloS one*, vol. 10, no. 8, pp. e0136955-e0136955, viewed 30 August 2019

Vasilevskis, E, Ely, E, Speroff, T, Pun, B, Boehm, L & Dittus, R 2010, 'Reducing iatrogenic risks: ICU-acquired delirium and weakness—crossing the quality chasm', *Chest*, vol. 138, no. 5, pp. 1224-1233.

Victoor A, Delnoij D, Friele R & J 2012, 'Determinants of patient choice of healthcare providers: a scoping review', *BMC Health Services Research*, vol. 12, p. 272.

Wallace, J, Lemaire, J & Ghalis, W 2009, 'Physician wellness: a missing quality indicator', *The Lancet*, vol. 374, pp. 1717-1721.

Warren, N 1994, 'The phenomena of nurses' caring behaviors as perceived by the critical care family', *Critical Care Nursing Quarterly*, vol. 17, no. 3, pp. 67-72.

Wasser, T, Pasquale, M.A, Matchett, S, Bryan, Y & Pasquale, M 2001, 'Establishing reliability and validity of the critical care family satisfaction survey', *Critical Care Med*, vol. 29, no. 1, pp. 192-196.

Watson, J & Frampton, S 2008, *Putting Patients First: Best Practices in Patient-Centered Care*, 2nd edn, e-book, Planetree,viewed December 2018, https://www.wiley.com/en-au/Putting+Patients+First%3A+Best+Practices+in+Patient+Centered+Care%2C+2nd+Edition-p-9780470377024

Wendler, D & Rid, A 2011, 'Systematic review: the effect on surrogates of making treatment decisions for others.', *Annals of International Medicine*, vol. 154, no. 5, pp. 336-346.

Wilcox, M, Vaughan, K, Chong, C, Neumann, P & Bell, C 2019, 'Cost-effectiveness studies in the ICU: a systematic review', *Critical Care Medicine*, vol. 47, no. 8, pp. 1011-1017.

Wiles, L & Stiller, K 2010, 'Passive limb movements for patients in an intensive care unit: a survey of physiotherapy practice in Australia', *Journal of Critical Care*, vol. 25, no. 3, pp. 501-8.

Williams, M 1989, *Needs of families of adult cardiac surgery patients during the intensive care stay*, masters theses, Grand Valley State University.

Winkelman, C, Johnson, K, Hejal, R, Gordon, N, Rowbottom, J, Daly, J, Peereboom, K & Levine, A 2012, 'Examining the positive effects of exercise in intubated adults in ICU: a prospective repeated measures clinical study', *Intensive Critical Care Nursing*, vol. 28, no. 6, pp. 307-18.

Wolfe, K, Patel, B, MacKenzie, E, Giovanni, S, Pohlman, A, Churpek, M, Hall, J & Kress, J 2018, 'Impact of vasoactive medications on ICU-acquired weakness in mechanically ventilated patients', *Chest*, vol. 154, no. 4, pp. 781-787.

Wong, P, Liamputtong, P, Koch, S & Rawson, H 2015, 'Families'experiences of their interactions with staff in an Australian intensive care unit (ICU): A qualitative study', *Intensive and Critical Care Nursing*, vol. 31, pp. 51-63.

Wyskiel, R, Chang, B, Alday, A, Thompson, D, Rosen, M, Dietz, A & Marstellar, J 2015, 'Towards expanding the acute care team: learning how to involve families in care processes A qualitative study', *Families,Systems and Health*, vol. 33, no. 3, pp. 242-249, viewed September 2019, https://psycnet.apa.org/record/2015-30035-001

Appendices

Appendix 1: Letter to staff

ROYAL PRINCE ALFRED
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30th April 2015

Dear.....

Family Assisted Passive Limb Exercising in the Intensive Care Setting

As you would be aware, Blue and Green ICUs are currently undertaking a Patient and Family Centred Care nursing research study:

"Family assisted passive exercising in the intensive care setting- A patient and family centred care study evaluating family and staff satisfaction, clinical outcomes of patients and healthcare efficiencies"

As part of the nursing team of Blue and Green ICU you will be directly involved in the study as you will be doing and or teaching the passive exercises.

While we intend that this research study will enhance our knowledge for the treatment of unconscious patients and their families in the future; it may not be of direct benefit.

The aim of the study is to see if involving family members in assisting the nursing staff in carrying out the passive limb exercises:

- Improves family and nursing staff satisfaction
- Improves clinical outcomes for the family member including: the number of days they need mechanical ventilation and the length of time they are in the Intensive Care Unit, and the hospital

I invite you now to take a few minutes to do the attached survey .

Further Information

The study is being conducted within RPAH by Judith Dixon, Clinical Manager of Critical Care as part of the requirements for a doctoral study. When you have read this information, Elaine Mc Gloin will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact her on 02 95157669.

Appendix 2: Patient screening tool

Bed No	Eligible	Reason If No							Approached	Reason if No
		ECMO	BMI	Trauma	Unstable	GCS > 8	MMT > 2	Other		
23										
24										
25										
26										
27										
28										
29										
30										
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Appendix 3: Information pamphlet for family participants-Active Unit

ROYAL PRINCE ALFRED HOSPITAL
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Family Assisted Passive Limb Exercising in the Intensive Care Setting

INFORMATION FOR PARTICIPANTS BLUE INTENSIVE CARE

Introduction

You are invited to take part in a research study into the effects of involving family or not in the carrying out of passive limb exercises on unconscious family members admitted into the Intensive Care Services.

The study is being conducted within this institution by Judith Dixon, Clinical Manager of Critical Care as part of the requirements for a doctoral study under the supervision of Associate Professor Jeff Patrick and Dr. Nazlee Siddiqui from the University of Tasmania.

Study Procedures

If you agree to participate in this study, you will be asked to sign the Participant Consent Form. You will then be asked to complete a questionnaire looking at the needs of relatives of unconscious patients admitted to the Intensive Care Services. This questionnaire should take approximately 5 minutes to complete. You will also be asked if you would like to participate in assisting nursing staff in carrying out passive limb exercises on your family member under the supervision of the nursing staff.

In addition, the researchers would like to have access to your family member's medical record to obtain information relevant to this study.

Risks

There are no foreseeable risks to your relative with this study as it is standard treatment for patients with your family member's illness. You will not be expected to carry out any further nursing care unless you feel that you would like to.

This study may not be suitable for patients with certain conditions, if you are concerned, the ICU team are happy to discuss this with you.

Benefits

While we intend that this research study will enhance our knowledge for the treatment of unconscious patients and their families in the future; it may not be of direct benefit.

The aim of the study is to see if involving family members in assisting the nursing staff in carrying out the passive limb exercises:

- Improves family and nursing staff satisfaction
- Improves clinical outcomes for your family member including: the number of days they need mechanical ventilation and the length of time they are in the Intensive Care Unit, and reduction in muscle wasting, pressure injury and infections

Costs

Participation in this study will not cost you anything, nor will you be paid.

Voluntary Participation

Participation in this study is entirely voluntary. You do not have to take part in it. If you do take part, you can withdraw at any time without having to give a reason. Whatever your decision, please be assured that it will not affect the medical treatment of your family member or your relationship with the staff who are caring for that family member.

Sometimes during the course of a study, new information becomes available about the treatment that is being studied. While you are participating in this study, you will be kept informed of any significant new findings which may affect your willingness to continue in the study.

Confidentiality

All the information collected from you and your family member for the study will be treated confidentially, and only the researchers named above will have access to it. The study results may be presented at a conference or in a scientific publication, but individual participants will not be identifiable in such a presentation.

Further Information

When you have read this information, Elaine Mc Gloin will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact her on 02 95157669.

This information sheet is for you to keep.

Ethics Approval and Complaints

This study has been approved by the Ethics Review Committee (RPAH Zone) of the Sydney Local Health District. Any person with concerns or complaints about the conduct of this study should contact the Executive Officer on 02 9515 6766 and quote protocol number X15-0059

Appendix 4: Information pamphlet for family participants Control Unit

Family Assisted Passive Limb Exercising in the Intensive Care Setting

INFORMATION FOR PARTICIPANTS GREEN INTENSIVE CARE

Introduction

You are invited to take part in a research study into the effects of involving family or not in the carrying out of passive limb exercises on unconscious family members admitted into the Intensive Care Services.

The study is being conducted within this institution by Judith Dixon, Clinical Manager of Critical Care as part of the requirements for a doctoral study under the supervision of Associate Professor Jeff Patrick and Dr. Nazlee Siddiqui from the University of Tasmania.

Study Procedures

If you agree to participate in this study, you will be asked to sign the Participant Consent Form. You will then be asked to complete a questionnaire looking at the needs of relatives of unconscious patients admitted to the Intensive Care Services. This questionnaire should take approximately 5 minutes to complete.

In this unit the nurses will be conducting the exercises.

In addition, the researchers would like to have access to your family member's medical record to obtain information relevant to this study.

Risks

There are no foreseeable risks to your relative with this study as it is standard treatment for patients with your family member's illness. This study may not be suitable for patients with certain conditions, if you are concerned, the ICU team are happy to discuss this with you.

Benefits

While we intend that this research study will enhance our knowledge for the treatment of unconscious patients and their families in the future; it may not be of direct benefit.

The aim of the study is to see if involving family members in assisting the nursing staff in carrying out the passive limb exercises:

- Improves family and nursing staff satisfaction

- Improves clinical outcomes for your family member including: the number of days they need mechanical ventilation and the length of time they are in the Intensive Care Unit, and reduction in muscle wasting, pressure injury and infections

Your family member is receiving the same passive limb exercises with the nursing staff alone and we want to see if there is any difference between the two units we are surveying

Costs

Participation in this study will not cost you anything, nor will you be paid.

Voluntary Participation

Participation in this study is entirely voluntary. You do not have to take part in it. If you do take part, you can withdraw at any time without having to give a reason. Whatever your decision, please be assured that it will not affect the medical treatment of your family member or your relationship with the staff who are caring for that family member.

Sometimes during the course of a study, new information becomes available about the treatment that is being studied. While you are participating in this study, you will be kept informed of any significant new findings which may affect your willingness to continue in the study.

Confidentiality

All the information collected from you and your family member for the study will be treated confidentially, and only the researchers named above will have access to it. The study results may be presented at a conference or in a scientific publication, but individual participants will not be identifiable in such a presentation.

Further Information

When you have read this information, Elaine Mc Gloin will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact her on 02 95157669.

This information sheet is for you to keep.

Ethics Approval and Complaints

This study has been approved by the Ethics Review Committee (RPAH Zone) of the Sydney Local Health District. Any person with concerns or complaints about the conduct of this study should contact the Executive Officer on 02 9515 6766 and quote protocol number X15-0059.

Appendix 5: Family consent form

ROYAL PRINCE ALFRED
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Family assisted passive exercising in the intensive care setting

PARTICIPANT CONSENT FORM

I, ... *[name]*

of.....*[address]*

have read and understood the information for participants on the above named research study

and have discussed the study with .....

I have been made aware of the procedures involved in the study, including any known or expected inconvenience, risk, discomfort or potential side effect and of their implications as far as they are currently known by the researchers.

I understand that my participation in this study will allow the researchers and others, as described in the information for participants, to have access to my family members medical record, and that this will contribute to a database and I agree to this.

I freely choose to participate in this study and data collection and understand that I can withdraw at any time.

I also understand that the research study is strictly confidential.

I hereby agree to participate in this research study.

NAME:.....**NAME OF WITNESS**.....

SIGNATURE:.....**SIGNATURE OF WITNESS**.....

DATE:.....

Appendix 6: Passive exercises pamphlet

(ALS 2004)

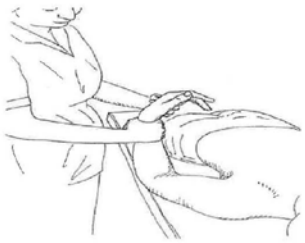
All exercises should be carried out 5 times. If resistance is met, do **NOT** force the movement. Do not carry out an exercise if there is a risk of dislodging any lines or tubing. Please do not carry out the exercises if there is a risk of hurting yourself. Please speak to the nurse if you are unsure.

Bending and Straightening the Fingers: Supporting the wrist with one hand, use the other hand to bend the fingers in towards the palm and then straighten outwards.

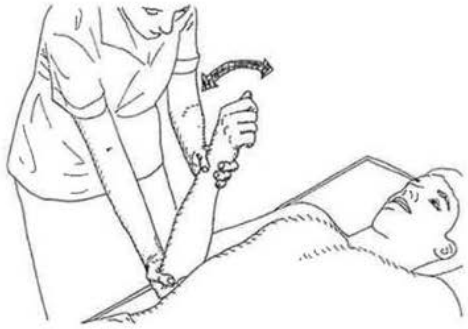
Bending the Wrist: Supporting the forearm, bend the wrist and then straighten

All exercises should be carried out 5 times. If resistance is met, do **NOT** force the movement. Do not carry out an exercise if there is a risk of dislodging any lines or tubing. Please do not carry out the exercises if there is a risk of hurting yourself. Please speak to the nurse if you are unsure.

Bending and Straightening the Fingers: Supporting the wrist with one hand, use the other hand to bend the fingers in towards the palm and then straighten outwards.



Bending the Wrist: Supporting the forearm, bend the wrist and then straighten



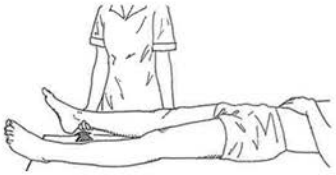
Bending the Elbow: Supporting the wrist in one hand and just behind the elbow with the other hand, bend the elbow and then straighten

Rotating the Forearm: Supporting the wrist in one hand and the elbow in the other hand, rotate the forearm

Rotating the Shoulder: Supporting the wrist in one hand and the elbow in the other hand, move the shoulder away from the chest and then back in

Lifting the Arm above the Head: Supporting the wrist in one hand and the elbow in the other, bring the arm above the head

Bending the Ankle: Supporting the ankle in one hand, bend the foot towards the head and then straighten



Moving the Hip: Supporting the ankle in one hand and the knee in the other, move the leg outwards and then back in

Bending the Hip and Knee (Start): Supporting the ankle in one hand and the knee in the other, bend the knee upwards towards the ceiling

Bending the Hip and Knee (Finish): Supporting the ankle in one hand and the knee in the other, bend the knee upwards towards the head

The exercise pamphlet was developed using the graphics from

Passive range- of - motion exercises, Everyday life with ALS, A Practical Guide, Muscular Dystrophy Association, USA

Appendix 7: Passive limb exercises record

F = Family performed exercises

N= Nurse performed exercises

N/A = Not appropriate to carry out exercises e.g. arterial line in situ

Day 1	Morning		Afternoon		Evening/Night	
Date:	Lt	Rt	Lt	Rt	Lt	Rt
Fingers						
Wrist						
Bending Elbow						
Rotating Elbow						
Rotating Shoulder						
Arm Above Head						
Ankle						
Moving Hip Outward						
Bending Hip & Knee						
Day 2	**Morning**		**Afternoon**		**Evening/Night**	
Date:	Lt	Rt	Lt	Date:	Lt	Rt
Fingers						
Wrist						
Bending Elbow						
Rotating Elbow						
Rotating Shoulder						
Arm Above Head						
Ankle						
Moving Hip Outward						
Bending Hip & Knee						

Appendix 8: Nurses' focus group participation letter

Dear

Family Assisted Passive Limb Exercising in the Intensive Care Setting

PARTICIPANT INFORMATION FOR NURSES FOCUS GROUP INTENSIVE CARE RPAH

Introduction

You are invited to take part in a research study into the effects of involving family or not in the carrying out of passive limb exercises on unconscious family members admitted into the Intensive Care Services.

The study is being conducted within this institution by Judith Dixon, Clinical Manager of Critical Care as part of the requirements for a doctoral study under the supervision of Professor Gary O'Donovan, Dr. Nazlee Siddiqui and Dr Kerryn Butler-Henderson from the University of Tasmania and in collaboration with Dr Greg Fairbrother, CNC Patient and Family Centred Care Research, SLHD and Elaine McGloin Clinical Nurse Consultant, ICU, RPAH.

Study Procedures

If you agree to participate in this study, you will be asked to sign the Participant Consent Form prior to joining a one hour focus group session with other nurses from your unit to be held on Thursday 21st[th] April 2016 at 2p.m. in the ICU Tutorial Room.

The discussion will be led by Judith and Elaine. The discussion will be taped for ease of transcription.

The purpose of the focus group is to obtain some qualitative information in relation to study that has been running in the Blue and Green ICUs since May 2015.

Risk

There are no foreseeable risks.

Benefits

While we intend that this research study will enhance our knowledge for the treatment of unconscious patients and their families in the future; it may not be of direct benefit.

The aim of the study is to see if involving family members in assisting the nursing staff in carrying out the passive limb exercises:

- Improves family and nursing staff satisfaction
- Improves clinical outcomes for the patient including: the number of days they need mechanical ventilation and

the length of time they are in the Intensive Care Unit, and reduction in muscle wasting, pressure injury and infections

Costs

Participation in this study will not cost you anything, nor will you be paid.

Voluntary Participation

Participation in this study is entirely voluntary. You do not have to take part in it. If you do take part, you can withdraw at any time without having to give a reason.

Confidentiality

All the information collected from you for the study will be treated confidentially, and only the researchers named above will have access to it. The study results may be presented at a conference or in a scientific publication, but individual participants will not be identifiable in such a presentation.

Further Information

When you have read this information, Judith will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact her on 02 95155346.

This information sheet is for you to keep.

Ethics Approval and Complaints

This study has been approved by the Ethics Review Committee (RPAH Zone) of the Sydney Local Health District. Any person with concerns or complaints about the conduct of this study should contact the Executive Officer on 02 9515 6766 and quote protocol number X15-0059.

Kind regards

Judith Dixon

Clinical Manager

Respiratory and Critical Care Services I Gastroenterology and Liver Services

Sydney Local Health District

+61 2 951 55346 fax +61 2 951 55134 mobile 0427008944 judy.dixon@sswahs.nsw.gov.au

Appendix 9: Nurses' focus group participant consent form

ROYAL PRINCE ALFRED
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Family assisted passive exercising in the intensive care setting

NURSING STAFF PARTICIPANT CONSENT FORM

I, ... *[name]*

of.....*[address]*

agree to participate in a nursing staff focus group on the above named research study

and have discussed the study with .....

I also understand that the research study is strictly confidential.

NAME:.....**NAME OF WITNESS**.....

SIGNATURE:.....**SIGNATURE OF WITNESS**.....

DATE:.....

Appendix 10: Focus group questions

Engagement questions What was the purpose of the study? What were the differences in the roles, between the active and control units?
Exploration questions What impact do you think the study and passive exercises had on the families? What impact do you think the study and passive exercises had on the patients? What impact do you think the study and passive exercises had on the nurses?
Exit question Is there anything else that you would like to say about the study that we have not covered?

Appendix 11: 30-item CCFNI and NMI

Modified CCFNI

Thank you for agreeing to take part in our survey to explore the needs of family members of unconscious patients admitted to our unit. We wish to know how important the following statements are to you. Please mark (X) the box which matches your response.

Thank you for agreeing to take part in our survey to explore the needs of family members of unconscious patients admitted to our unit. We wish to know how important the following statements are to you. Please mark (X) the box which matches your response.

Instructions Please use black or blue ink ONLY. OOO Please leave blank if not applicable	How IMPORTANT is this need to you? 1 = Not Important 2 = Slightly Important 3 = Important 4 = Very Important	Was this need MET? 1 = Never Met 2 = Sometimes Met 3 = Usually Met 4 = Always Met
1. To feel accepted by the hospital staff	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
2. To talk to the doctor every day	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
3. To know how the patient is being treated	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
4. To talk about feelings	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
5. To have directions regarding what to do at the bedside	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
6. To have visiting hours start on time	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
7. To know why things were done for the patient	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
8. To know exactly what was being done for the patient	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
9. To have someone concerned with the family member's health	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
10. To see the patient frequently	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
11. To be told about transfer plans	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
12. To know about the types of staff taking care of the patient	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
13. To be assured that the best possible care was being given to the patient	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4

14. To be called at home about changes in the patient's condition	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
15. To have friends nearby for support	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
16. To help with the patient's physical care	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
17. To talk with the nurse each day	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
18. To talk about the possibility of the patient's death	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
19. To have a telephone in the waiting room	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
20. To know the prognosis	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
21. To have explanations of the environment before going in	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
22. To feel there was hope	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
23. To have a specific person to call at the hospital when not there	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
24. To have visiting hours or restrictions changed for special condition	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
25. To receive information about the patient once a day	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
26. To have questions answered honestly	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
27. To feel that hospital personnel cared about the patient	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
28. To be told about other people who could help with problems	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
29. To know specific facts about the patient's condition	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4
30. To have explanations given in terms that are understandable	O 1 O 2 O 3 O 4	O 1 O 2 O 3 O 4

Appendix 12: Family assisted passive exercise instrument (excluding CCFNI, NMI and FSS data) an example of one patient's de-identified data

Comment [JD1]: E1 comment 26 instrument added

Family assisted passive exercise instrument (FAPEI)	
Patient	1
Unit	active
Date of consent	15.5.2015
Medical Record Number	xxxxx
Gender of relative	Female
Relationship to patient	Wife
Age of patient	66
Gender of patient	Male
Ethnicity	Cantonese
Presenting problem	Liver failure
From local health district	No
Retrieved from another hospital	Yes
Ventilator hours	33
Length of stay days ICU	2
Length of stay days hospital	56
Survived	No
Right mid-forearm cm.	20.5
Left mid-forearm cm	20.5
Right mid-upper arm	22.5
Left mid-upper arm	22
Right mid-thigh	41
Left mid-thigh	38.5
Surveys given	Yes
Surveys completed	Yes

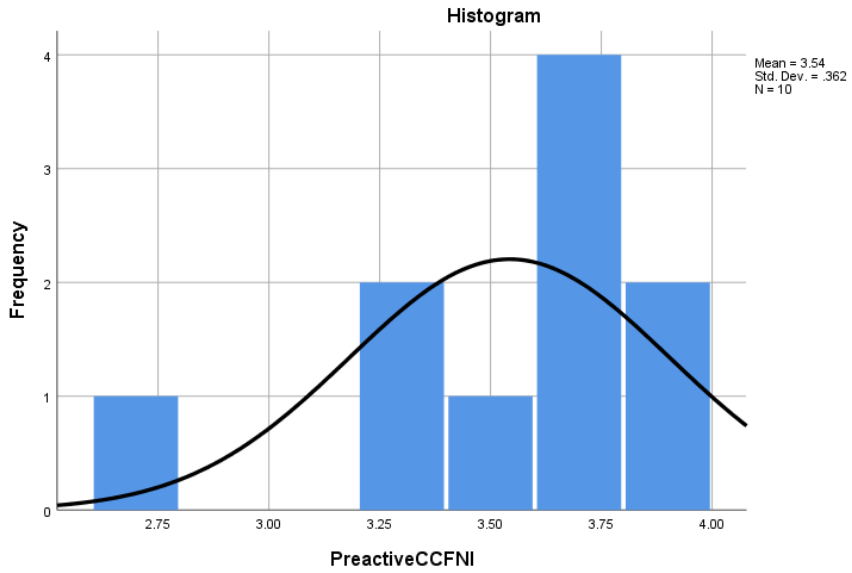
Appendix 13: Pre-test distribution of the CCFNI data in the active unit (family)

Statistics

N		10
	Missing	2
Mean		3.5429
Median		3.6667
Std. Deviation		.36200
Skewness		-1.756
Std. Error of Skewness		.687
Kurtosis		3.578
Std. Error of Kurtosis		1.334

Pre-test CCFNI active unit

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	2.67	1	8.3	10.0	10.0
	3.30	1	8.3	10.0	20.0
	3.37	1	8.3	10.0	30.0
	3.57	1	8.3	10.0	40.0
	3.67	2	16.7	20.0	60.0
	3.70	1	8.3	10.0	70.0
	3.73	1	8.3	10.0	80.0
	3.86	1	8.3	10.0	90.0
	3.90	1	8.3	10.0	100.0
	Total	10	83.3	100.0	
Missing	System	2	16.7		
Total		12	100.0		



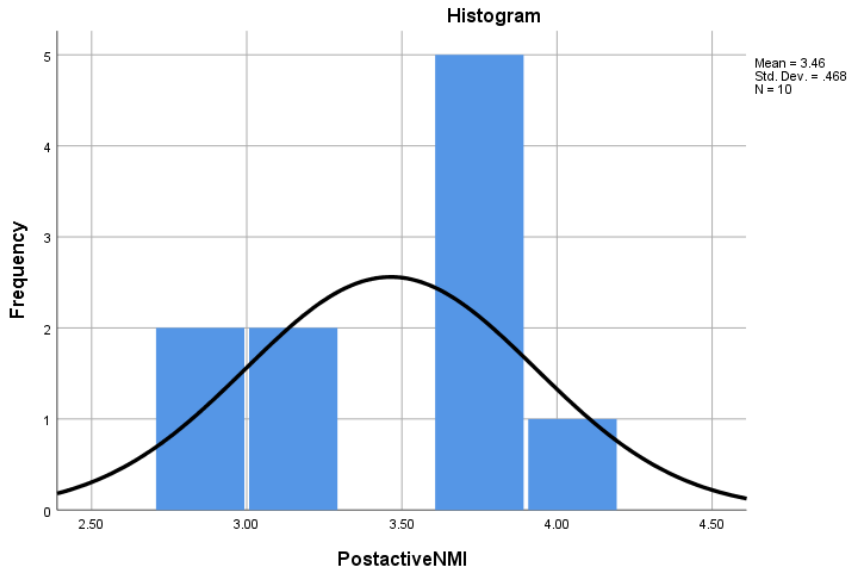
Appendix 14: Post-test distribution of the NMI data in the active unit

Statistics

N	Valid	10
	Missing	2
Mean		3.4639
Median		3.6937
Std. Deviation		.46756
Skewness		-.520
Std. Error of Skewness		.687
Kurtosis		-1.620
Std. Error of Kurtosis		1.334

Post- test NMI active unit

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	2.73	1	8.3	10.0	10.0
	2.87	1	8.3	10.0	20.0
	3.07	1	8.3	10.0	30.0
	3.11	1	8.3	10.0	40.0
	3.62	1	8.3	10.0	50.0
	3.77	1	8.3	10.0	60.0
	3.81	1	8.3	10.0	70.0
	3.83	2	16.7	20.0	90.0
	4.00	1	8.3	10.0	100.0
	Total	10	83.3	100.0	
Missing	System	2	16.7		
Total		12	100.0		



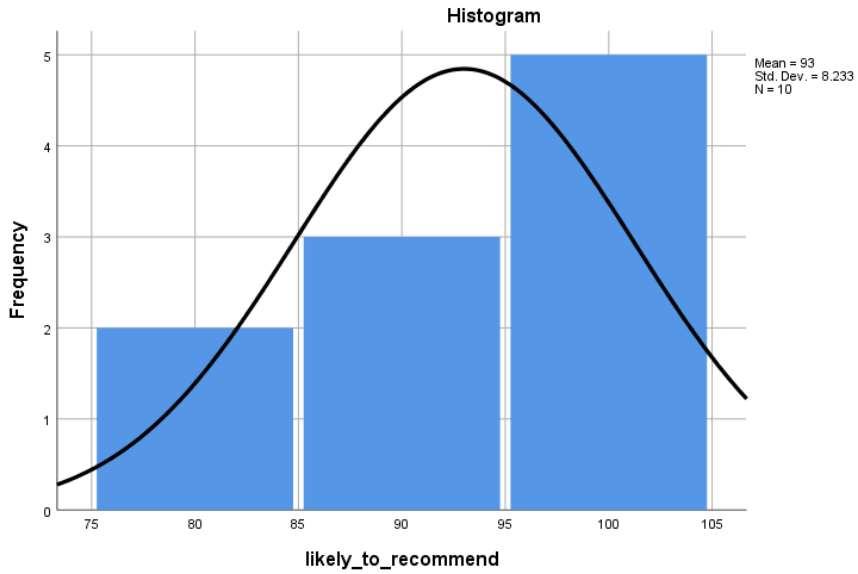
Appendix 15: Family Feedback Survey distribution analysis active unit

Likely to recommend

N	Valid	10
Mean		93.00
Median		95.00
Std. Deviation		8.233
Skewness		-.687
Std. Error of Skewness		.687
Kurtosis		-1.043
Std. Error of Kurtosis		1.334
Minimum		80
Maximum		100

Likely to recommend

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	80	2	16.7	20.0	20.0
	90	3	25.0	30.0	50.0
	100	5	41.7	50.0	100.0
	Total	10	83.3	100.0	
Total		12	100.0		



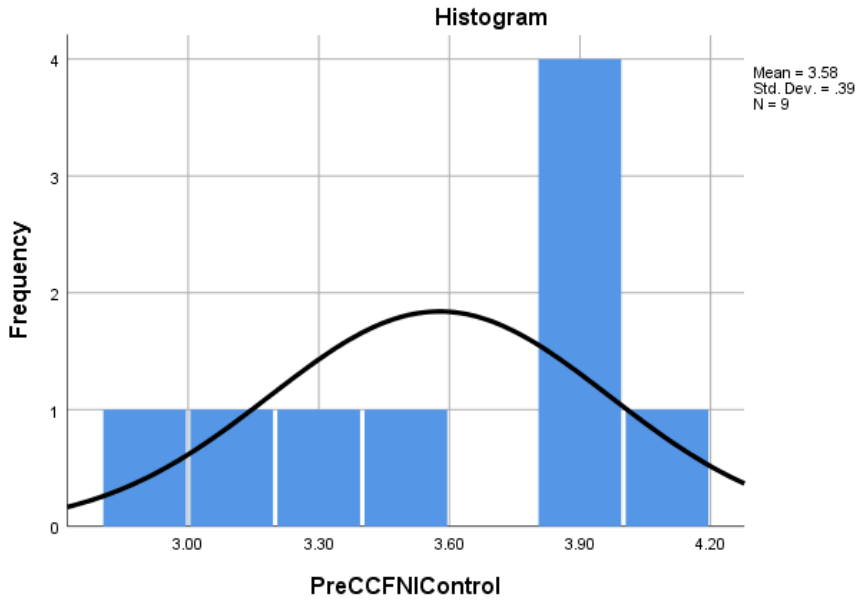
Appendix 16: Pre-test distribution of the CCFNI data in the control unit (family)

Statistics

N	Valid	9
	Missing	0
Mean		3.5772
Median		3.8000
Std. Deviation		.39029
Skewness		-.559
Std. Error of Skewness		.717
Kurtosis		-1.456
Std. Error of Kurtosis		1.400
Minimum		2.97
Maximum		4.00

Pre-test CCFNI control unit

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	2.97	1	11.1	11.1	11.1
	3.07	1	11.1	11.1	22.2
	3.33	1	11.1	11.1	33.3
	3.40	1	11.1	11.1	44.4
	3.80	1	11.1	11.1	55.6
	3.83	1	11.1	11.1	66.7
	3.86	1	11.1	11.1	77.8
	3.93	1	11.1	11.1	88.9
	4.00	1	11.1	11.1	100.0
	Total	9	100.0	100.0	



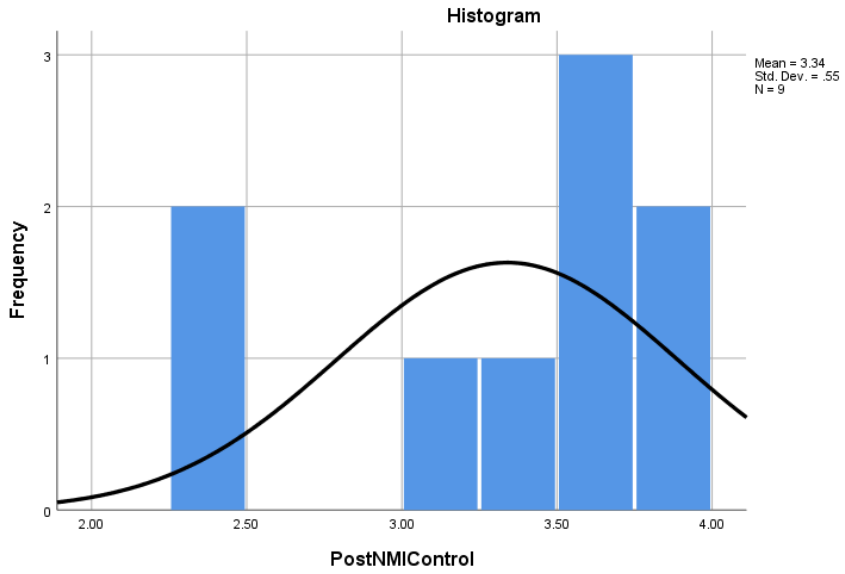
Appendix 17: Post-test distribution of the NMI data in the control unit (family)

Statistics

N	Valid	9
	Missing	0
Mean		3.3392
Median		3.5714
Std. Deviation		.55045
Skewness		-.869
Std. Error of Skewness		.717
Kurtosis		-.560
Std. Error of Kurtosis		1.400
Minimum		2.46
Maximum		3.90

Post NMI Control

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	2.46	1	11.1	11.1	11.1
	2.47	1	11.1	11.1	22.2
	3.20	1	11.1	11.1	33.3
	3.25	1	11.1	11.1	44.4
	3.57	1	11.1	11.1	55.6
	3.60	1	11.1	11.1	66.7
	3.70	1	11.1	11.1	77.8
	3.90	1	11.1	11.1	88.9
	3.90	1	11.1	11.1	100.0
	Total	9	100.0	100.0	



Appendix 18: Family feedback distribution control unit (family)

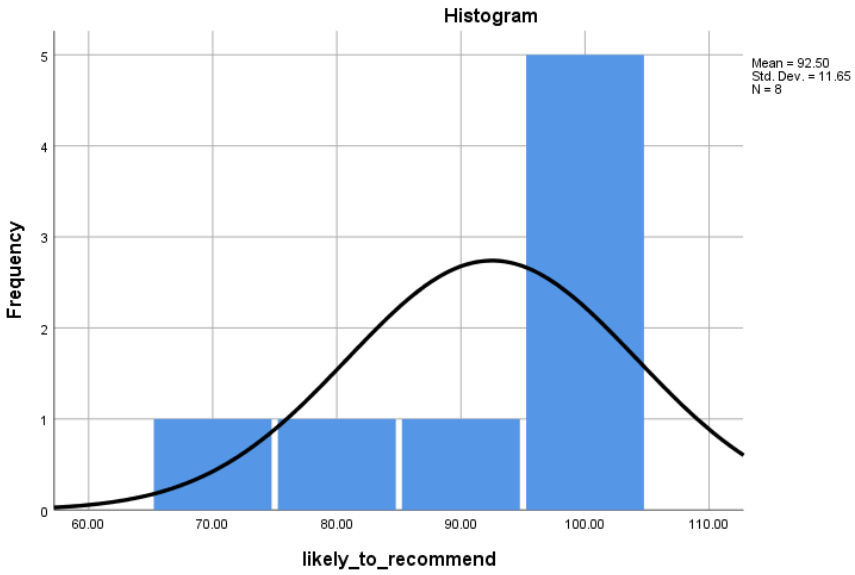
Statistics

Likely to recommend

N	Valid	8
	Missing	1
Mean		92.5000
Mode		100.00
Std. Deviation		11.64965
Skewness		-1.355
Std. Error of Skewness		.752
Kurtosis		.620
Std. Error of Kurtosis		1.481
Minimum		70.00
Maximum		100.00

Likely to recommend

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	70.00	1	11.1	12.5	12.5
	80.00	1	11.1	12.5	25.0
	90.00	1	11.1	12.5	37.5
	100.00	5	55.6	62.5	100.0
	Total	8	88.9	100.0	
Missing	System	1	11.1		
Total		9	100.0		


Histogram
Mean = 92.50
Std. Dev. = 11.65
N = 8
Frequency
0
1
2
3
4
5
60.00
70.00
80.00
90.00
100.00
110.00
likely_to_recommend

Appendix 19: Modified Nursing Stress Scale instrument

Family Assisted Passive Exercising in the Intensive Care Setting
Staff Survey

Below is a list of situations that commonly occur on a hospital unit. For each item indicate by a means of a check (x) how often on your present unit you have found the situations to be stressful. Your responses are strictly confidential. Thank you for taking the time to complete this survey

1. Please indicate your years of nursing experience

0 – 3	4 – 6	7 – 10	> 10
☐	☐	☐	☐

2. Please indicate your years of ICU experience

0 – 3	4 – 6	7 – 10	> 10
☐	☐	☐	☐

3. Performing procedures that patients experience as painful

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

4. Feeling helpless in the case of a patient who fails to improve

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

5. Listening or talking to a patient about his/her approaching death

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

6. The death of a patient

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

7. The death of a patient with whom you developed a close relationship

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

8. Physician not being present when a patient dies

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

9. Watching a patient suffer

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

10. Criticism by a physician

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

11. Fear of making a mistake in treating a patient

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

12. Disagreement concerning the treatment of a patient

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

13. Making a decision concerning a patient when the physician is unavailable

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

14. Feeling inadequately prepared to help with the emotional needs of a patient's family

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

15. Being asked a question by a patient for which I do not have a satisfactory answer

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

16. Feeling inadequately prepared to help with the emotional needs of a patient

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

17. Lack of an opportunity to talk openly with other unit personnel about problems on the unit

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

18. Lack of an opportunity to share experiences and feelings with other personnel on the unit

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

19. Lack of an opportunity to express to other personnel on the unit my negative feelings toward patients

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

20. Conflict with a supervisor

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

21. Floating to other units that are short-staffed

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

22. Difficulty in working with a particular nurse (or nurses) outside the unit

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

23. Criticism by a supervisor

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

24. Difficulty in working with a particular nurse (or nurses) on the unit

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

25. Breakdown of computer

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

26. Unpredictable staffing and scheduling

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

27. Too many non-nursing tasks required, such as clerical work

I.

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

28. Not enough time to provide emotional support to a patient

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

29. Not enough time to complete all of my nursing tasks

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

30. Not enough staff to adequately cover the unit

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

31. Inadequate information from a physician regarding the medical condition of a patient

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

32. A physician ordering what appears to be inappropriate treatment for a patient

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

33. A physician not being present in a medical emergency

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

34. Not knowing what a patient or a patient's family ought to be told about the patient's condition and its treatment

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

35. Uncertainty regarding the operation and functioning of specialized equipment

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

36. Teaching family members (added)

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

37. Talking to family members (added)

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

38. Delivering passive exercises to patients (added)

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

39. Discussing clinical care with family members (added)

Never	Occasionally	Frequently	Very Frequently
☐	☐	☐	☐

Appendix 20: Cronbach's alpha: pre-test complete results

Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha based on standardized Items	N of Items
.839	.840	4

Item Statistics

	Mean	Std. Deviation	N
teaching_family	2.08	.677	100
talking_to_family	2.42	1.017	100
passive_exercises	1.89	.723	100
clinical_discussions	2.25	.880	100

Summary Item Statistics

	Mean	Minimum	Maximum	Range	Maximum / Minimum	Variance	N of Items
Item Means	2.160	1.890	2.420	.530	1.280	.052	4

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
teaching_family	6.56	4.976	.693	.520	.797
talking_to_family	6.22	3.567	.761	.658	.761
passive_exercises	6.75	5.422	.469	.270	.873
clinical_discussions	6.39	3.877	.829	.696	.720

Appendix 21: Cronbach's alpha: post-test complete results

Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.806	.799	4

Item Statistics

	Mean	Std. Deviation	N
teaching_family	2.11	.689	81
talking_to_family	2.65	.989	81
passive_exercises	1.89	.612	81
clinical_discussions	2.42	.878	81

Summary Item Statistics

	Mean	Minimum	Maximum	Range	Maximum / Minimum	Variance	N of Items
Item Means	2.269	1.889	2.654	.765	1.405	.114	4

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
teaching_family	6.96	4.211	.666	.481	.743
talking_to_family	6.42	2.972	.768	.610	.681
passive_exercises	7.19	5.178	.365	.153	.855
clinical_discussions	6.65	3.379	.749	.620	.688